The Power Of Patient Advocacy: Making Change From The Front Lines Transcript

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Introduction and Guest Background

Hi, and welcome to another episode of the Healing Lyme Summit 2.0. I'm your host, Doctor Maria Hinchey, and in today's episode, we're going to be talking with Alex Aresco, who advocates for both patients and physicians and is a dear friend of mine.

Ali is the founder of Moscow Public Relations and Communications, and brings a wealth of experience spanning both entertainment and healthcare, public relations as well as talent relations.

Four years ago, her personal health journey led her to specialize in health care, PR and leveraging her lived firsthand experience with chronic disease and her expertise as a professional patient.

She's crafted effective communication strategies. Ali has achieved notable media coverage for her clients and prestigious publications like The New York Times, The Wall Street Journal, Forbes, and many more.

With a track record of securing over 250 prominent placements in the past year alone. Her dedication to building a strong media relationship is very evident.

Ali has raised significant funds for tick borne illness research and has actively lobbied in Washington, D. C.. She also sits on the executive Board for a national nonprofit, Project Lyme and the Emerging Leader Board for Nashville based cancer nonprofit, the Nashville Wine Auction.

Welcome, Ali. Thank you so much for being here today. Thank you for having me. This is such an honor, and I'm so happy that I get to talk to you. So I know meets here first thing in the morning.

It's great. So before we get into everything that you do to help patients and practitioners in the community of Lyme, do you mind sharing your story with our listeners?

Yes. So probably like almost all of your patients and a great majority of listeners, I was perfectly healthy. I was never expecting to get sick. And, I like to say that I'm a city girl through and through.

I was living in Chicago, was not really spending a lot of time, you know, in the woods or in wooded areas or any place that you would think that ticks like to hang out.

But then I went up to Northern Michigan, with my husband and his family where he's from. And I did, you know, the whole thing where I wore a hat and I wore tick spray and tall socks and, So my family's originally from the East Coast, so my mom, like, kind of knew enough to say, like, hey, wear a hat in the woods.

Lyme Diagnosis and Personal Story

And, took preventative measures and somehow still came home from that trip with cold and flu symptoms. Went to see my GP at the time that was at a major hospital system in Chicago, who told me I, oh, you just have a summer.

You just have a summer cold. Went back two weeks later. Where? Oh, you must have you must have a stomach flu. And this went on for two years. Until finally a specialist looked at me and said, have you ever been tested for Lyme disease?

And one of the really challenging things about that whole situation and it it taking two years, which I know unfortunately is it's short compared to most people's journeys was like two months in to when I was having these cold and flu symptoms and getting worse.

My mom went with me to a GP appointment because I don't care how old you are, sometimes you just need your mom to help advocate for you and asked, could she have Lyme disease?

Can we test her for Lyme disease? And the GP refused and said, oh, it's so rare. It's a it's a waste of money. It's a waste of insurance money. We're not going to do that.

Wow. Yeah. So it took me two years to get diagnosed and, I am one of those, like, very classic cases. I have neurological Lyme and that Basia and Bartonella and all of the things, but I, I will say I'm mostly well now.

So like when I share my story, I always like to share that. And knowing that it took me eight years to get there. But it can happen, you know, and I feel like I'm proof of that.

Yeah, well, thank God you are mostly. Well, do you want to share what your treatment journey was like? You know, like how what pieces of the puzzle you used to get yourself, mostly.

Well. Yeah. I mean, it really. I feel like Lyme and Tick-Borne conditions. It's like peeling an onion. There's a lot of layers, and I feel like you do a lot of therapies where you don't notice this immense, immediate change.

But it's not until you kind of look back and you're like, oh, yeah, that was a little step forward. And every little step forward really, really adds up at the end of the day. So, I started my treatment journey, with my first, the almost nine years ago now, who put me on Doxy Cycling and Herbs and it helped.

But it didn't obviously get me to where I needed to be. And I have done a little bit of everything. I've done I. V. antibiotics, which which did help, but ultimately, like, once again, for my body, it was not what kind of pushed me over the edge of wellness.

It wasn't until I found out that I had this autonomia and specific antibody deficiency, and we started kind of peeling away some of the co-morbid oddities and then got to really like the Lyme and tick borne conditions, that I feel like I really started to get like a leg up on my therapeutic journey.

And then eventually, was connected with Doctor Horowitz and started doing dabs on therapy. And for me, that's that's what really, really helped me. And I feel like what got me probably 80 to 85% better, you know, most of the time.

And I, you know, I my Bartonella is still like rearing its ugly head. So that can be very challenging. So I have a little bit of a ways to go. But yeah, if there's any other treatment you want me to specifically talk about, I'm happy to do so.

Yeah. I'm not looking for anything specific. Just for what? You, you know, what you really felt was helpful. And even if there's things, you know that and every person is different, you know, but if there are things that you didn't find all that helpful.

But how long ago did you do Dobson therapy? It was about a year and a half ago. And I, I did three rounds of it. The first round was about a month, and then I did two pulses.

And I felt like every time I did it, I had more symptoms. Really, like, peel away. And it wasn't, you know, you do this therapy for two weeks and you're exhausted after.

But I always like to say, for me, it's not the worst treatment I've ever done. It's not the sickest I've ever felt. It's not the worst I've ever heard.

But you are just exhausted after. And then for me, typically it's about four weeks post therapy that I. I start waking up and I'm like, wait, I have a little bit more energy.

I'm not, you know, in pain. My brain fog is a little bit better. Which is a really good feeling. Yeah, it's a relief. Yeah.

So do you do anything? Do you do any sort of maintenance therapy?

Sounds. Yeah. I, I mean, if my symptoms ever, like, fully come back, I would absolutely do again.

Treatment Journey and What Helped Most

And I know there's other people that have had to do that. And I'm pretty realistic about the fact that Lyme and borne conditions, you do have to do some type of maintenance and you do have to manage it.

I take I don't know if this is a traditional or nontraditional approach, but I, I, you know, a, a really anti-inflammatory diet. I avoid gluten, and I feel like that is maintenance in itself for inflammation.

I do red light therapy almost every single morning. I have an infrared sauna that I do to, like, detox, and I still, I take a binder and I get in the sauna and I detox.

And then I take, you know, I do herbal therapy, to support not just my, my adrenals and my nervous system, but also, I'm just a high anxiety individual.

So I take, a handful of different herbs, you know, to support my anxiety and my mental health. And then I take, like, a liposomal, you know, glutathione, iron and magnesium and vitamin C, and just kind of like the basics to keep my system healthy and give me a little bit of protection.

And that's pretty much what I do for maintenance. It's great. If you had one piece of advice to share with our listeners who are struggling with chronic disease, whether it is tick borne related or not, what would it be?

I would say, you know, something I didn't realize in my own journey when I was really sick and in a lot of pain and unable to get out of bed, was that that moment of severe, severe illness was temporary.

I thought that I was going to feel that way forever. So I guess my piece of advice from like patient to patient, whoever is listening or watching this is if you're in extreme pain, if you are extremely ill, try to remember that this moment is temporary and that everything you do to support your body will help you take a small step forward.

And try to have that playing in your brain. I know, despite how hard it is, but I think it's really important to remember so that you can keep having hope.

You know that it will get better someday. Because I really, I believe that because of clinicians like you and like Doctor Horowitz, it will get better for people.

Yeah, I believe that too. And there's a lot of resources out there for patients. You know, we're going to talk about project Lyme in a minute. But you know for patients and practitioners there is the international Lyme and Associated Diseases Society.

There's Lyme disease.org. There's Project Lyme again, which we're going to talk about. But you know, there's so many resources out there to find a Lyme literate practitioner that can really help you.

And I know that it's super, super hard in the moment, but I think sometimes, you know, we feel so bad and our brains are so on fire that it's like, you know, say that really what you're feeling is like a seven out of ten, like we will spiral, you know, into a 12 out of ten with the anxiety and almost like the panic setting in.

And it's like, you know, I tell my patients all the time if you can just sort of like. And I know it's hard. I mean, I've been there, right? We've both been there.

But if we can kind of pause and breathe right and try to do like some of that switching out of the fight or flight into, like parasympathetic, you know, soothe the vagus nerve, we can kind of bring ourselves back down and, you know, breath is a very powerful thing.

And oxygen is a very, very powerful Madison. Right. And sometimes we just need to change our breathing and change our outlook. And it can literally change like the physiology that's going on in our body at that moment.

Yeah, absolutely. It is. It's important. And there's so many tools like breath that we have within ourselves. And it's just knowing and remembering to tap into it.

I think remembering. That's the huge part of. Remembering. I need that reminder all the time. Okay, so tell us, tell us about your role in Project Lyme and tell us how you got involved and tell us what Project Lyme does.

Yeah. So I adore Project Lyme. I feel so lucky to be involved.

Maintenance, Self-Care, and Hope

Project Lyme is a 500 and 1C3 that is based on the East Coast, but serves a national audience and now, they do some international work, which I'm happy to share a little bit about, and some of the cool experiences we had over the summer.

But they fund research from major institutions and quite literally the best researchers, in the world, online and tick borne diseases and they also support things like education and awareness and patient advocacy.

So, for example, we are a funder of center for Lyme Action, which is a 500 and C4 lobbying group that lobbies Congress and Senate and our government for change, for people with Lyme and tick borne conditions and research dollars.

You know, at the federal level, which is really important. We've never had that before. We fund things like national surveys, where we filmed, for PSA online and tick borne diseases, and we ran those on TV and, you know, it was really, really cool to kind of track like when the states were running to project Lyme's, website views because you kind of say like, okay, PSA is what's that really doing?

And our website clicks during the months that those are running, they went up immensely, which was so cool to see that people were seeing like, hey, if you have mystery symptoms, it could be Lyme.

Check out Project lyme.org and people are doing it and putting the dots together. And that's so important. So Project Lyme does a whole host of things that I feel really good about supporting, and I am lucky enough.

I sat on project Lyme's executive board, and actually became the chair of the executive board this past summer. So essentially what I do is I help to contribute to, deciding what the organization will fund, where we will put our energy, where we will put our resources, brainstorming on how can we best serve patients, which as a patient myself, I think is really important.

Yeah. So that's what I do with Project Lyme. And I, you know, I think my. My involvement was born out of needing something to channel my energy into that was just for like, the good of other people.

Because everything I do with Project Lyme is purely volunteer based. I'm not making anything off of it. Obviously. And I think that when you are sick, you just have a lot of stagnant energy and sometimes, you know, a lot of angry energy, because of what you've gone through and what you've experienced.

And, and for me, I just needed something to channel that into, so that's why I started, you know, raising money for, for non-profits and getting involved. And, it's been a really, really good thing.

And, you know, for anybody listening that you're like, oh, that intrigues me. Just know that nonprofit work and like, this type of volunteer work, I can meet you where you're at, you know, we have some people that volunteer for an event here or there, or we have some people that volunteer, you know, to help us, you know, with, like, contributing to a blog piece, which is very, you know, low, low energy input and things like that.

And there's a way to give back and and to be able to channel your energy into something and, and create purpose, you know, put purpose to your pain. That doesn't have to be as intensive as, as what I do.

Yeah, I think that's a really good point, too. And I mean, a lot of times, at least a lot of the patients that I've had, they've been so sick and debilitated that it's like, you know, some of them can't work anymore.

Right? And they they feel like their life has become meaningless and they're very much in themselves and in their heads. And I think, you know, when you have the opportunity to do something like this, I mean, obviously it's it's a distraction from what is going on.

And if you, you know, can work at your own pace and whatnot. Like, obviously that's super helpful for a line patient. But I think that feeling that like your suffering and what you've been through is actually making a difference in somebody else's life, like somehow that's very healing.

Like it's actually very, very healing and helps, I think, to move you forward and out of that really stuck sick victim role. I am very empowering. I think we don't talk enough about that.

When you get sick, you kind of go through this grieving process where you're grieving your old self, you're grieving who you were, are you're grieving, the way you lived and the freedom you had and, I think people really beat themselves up over that process and think it's abnormal.

And in reality, everyone goes through it.

Project Lyme and Patient Advocacy

And I exactly like you're saying I was so sick, I had to stop working for two years and, really realized that my career was my identity. You know, I was in entertainment PR before I got sick and had my own firm, as I do now.

But now I'm in health care, PR and when I lost that, I just was like, I don't know who I am. I don't know what I enjoy, I don't know what I like to do because I didn't have that to focus on.

And I think my volunteer work, my philanthropic work really helped me to kind of figure out like, oh, actually, I really enjoy this. And I really enjoy giving back. And, it also helped me to meet other people that were also Lyme patients, which I think is really important to have, you know, a support system.

If, you know, if you're lucky enough, like, like I was to have a really strong support system in my family, in my husband. That's great, but it's hard because, you know, there's a saying, you don't get it unless you get it.

So, like, there's some times where I'm like, I just need to talk to another patient and be like, you know, is your lower foot pain driving you crazy, too?

You know, because I know that they're they know exactly what I'm talking about. Whereas somebody else is like, well, why? Why is it happening? What what is that?

Is it really that bad? And you're like, yeah. So yeah, the sense of community is huge. And I think, you know, it's funny, I joke. So I'm the type of naturopathy doctor that like I won't recommend a treatment usually unless I've already done it.

So like the big joke is like, oh yeah, you know, I had Lyme and the bees and Bartonella and all of that, so that, like, I knew firsthand what it was like to experience it, what the treatment is, how you get through it, how you heal yourself, you know, that whole thing. But, yeah, it's hard because your family doesn't get it.

A lot of times you're you're, you know, you're trusted physician and medical professionals don't get it. Your husband doesn't get it. Nobody gets it. And you feel like a constant whiner and complainer and still misunderstood.

So I think you start to turn inward. And yeah, having that sense of community where like, you don't have to try to explain yourself ad nauseum and people just get you, again, is very, very helpful, like on the healing journey.

So I think getting involved with any sort of like nonprofit or patient advocacy group, you know, can be immensely healing. Yeah. And I also want to mention it's not Project Lyme related at all, but, Global Lyme Alliance has something called a peer to peer foundation where essentially you can register for this program and they will match you with somebody who also has Lyme and tick borne conditions, but maybe as a little bit more experience than you with, so they just have an understanding, but they kind of become your body to go through this journey with.

And the program was actually established by one of my very, very dear friends, that passed away, years ago. But I really feel like it was her, like, gift to the community and to the world, because I know it's really helpful for people and nothing else like it really exists.

So I would definitely check out Global Alliance as Peer to peer Foundation. If you're somebody listening to this that just needs to connect with somebody else who gets you.

Yeah. That's awesome I don't know, that sounds kind of like a sponsor. Yeah. Yeah, yeah, that kind of. So it's a great way to say it. Cool. All right.

So for the practitioners that are listening to our episode here, tell us about your PR firm and tell us I one of the things that I love about what you do is that you're not a normal PR firm, right?

Like, first of all, you have your niche with, you know, chronic illness and tick borne disease. But beyond that, you know, not only are you connecting these practitioners to educational opportunities, right, and connecting everyone else to them for the education, but you really advocate for our protection and to make sure that we are doing things in a way that we're not going to risk our licenses and that we're not going to get in trouble, because, you know, this is a very medical political disease.

And in a lot of states, practitioners really open themselves up to scrutiny for treating outside of the infectious disease, guidelines. So tell us more about that.

Yeah. So like I mentioned earlier, I like to say in my first life. So before I got sick, I was an entertainment publicist. I worked with celebrities and on TV shows and, all of the things.

And then I got sick and I, you know, became a consumer of the health system myself and realized that there is a disconnect between how, you know, clinicians and health care companies and brands speak to their patient consumers.

And I realized that because of my PR background, coupled with my lived experience as a patient, plus my experience philanthropically raising money where I had the opportunity at a lot of these events to like, quite literally meet thousands of patients across the US and hear their stories and hear what their gaps were.

Between those three things, I was like, hey, I think I can I can help these clinicians and I can help these health care brands.

PR for Practitioners and Media Strategy

And to connect those dots, to better serve their practice and themselves, but also to better serve the patient community. So I like to say we're a mission driven PR firm.

We only work with clients that I truly feel like are impacting patient lives for the better. And I feel like those are the voices that need to be elevated into things like mainstream media, onto things like podcasts, in formats like social media, and other nontraditional media, so that we have real factual voices providing information on tick borne disease, on the state of disease in the US, on things like nutrition and supplementation, and alternative therapies and health. So I take that responsibility, you know, really seriously that I get to help elevate these voices, into these

different media formats and, I'm very careful about who I place my clients with to have these conversations and helping to ensure that the journalists and the outlets, you know, that my clients speak with, really have the best interest of of my client, but also of the topic, right, that we're talking about.

Because when I get a media request on something like Lyme disease, I have to be able to figure out, is this an altruistic like reporting? Is this like an altruistic request, or is this something that, like, I don't want my client associated with?

So I feel very lucky that I get to do the work that I do and, support patients in tandem with supporting, you know, clinicians who who deserve it, you know, and they need it.

It's great. So if there's a practitioner that wanted to work with you, how would they find you? Typically just through my website, which is ein Rasco pr.com.

And there's like a sample of our work. And I also have been trying to build just like free resources for clinicians that are just trying to dip their toe in and see if, you know, communications and speaking with the media and doing podcast interviews is something they're interested in.

So I have like a little media like e-book and a do's and don'ts of speaking with the media. And there's a pretty robust free blog section on our website that is just meant to support health care providers.

So great. And for, people trying to get in touch with Project Lyme, what is their website? Project Lyme? Okay.

Final Advice and Closing Remarks

I have an email that they can reach out to and ask questions and, anything they need. But the team over there is pretty great. They are. I can say that firsthand.

They're wonderful. Okay, so if you have any last words of advice for our listeners. You know, once again, I would just say, don't give up hope. And I know that it's really hard to see when you're in the thick of it.

But you will emerge and life might look a little different, but it doesn't mean you know that it's bad. I can honestly say that it was a long journey for me, and it it's still not over.

But I do feel like through this pain, I found my life's purpose that I never would have found without it. Yeah. So just just don't lose hope. And I'm.

If you ever need any, you know, I'm always here. That's wonderful. Thank you so much. Thanks for joining me today. Thank you. Yeah. And thank you to everyone at home listening.

I hope you enjoyed this episode and I hope it helps you on your journey to healing Lyme. We'll see you next time. Bye bye.