From Hashimoto’s 411 to Autoimmune 411: A Patient Advocate’s Journey With Founder Alice McDonnell Transcript

(Transcripts are generated by AI and may contain errors)

Introduction to Hashimoto's Advocacy

Have you ever wondered why is it that not a lot of doctors know what to do when you have an autoimmune condition or Hashimoto's. It's kind of crazy but a oftentimes people who have the very same condition and that have walked the shoes that we've walked to.

And honestly, as a healthcare professional, I find that a lot of my fellow healthcare professionals become passionate about a condition, and really figure out how to treat it because they worked with it themselves.

Now, personally for me, I was never interested in the thyroid during pharmacy school. I thought it was very, very boring until, of course, i was diagnosed with Hashimoto's myself and some crazy symptoms that would not budge with thyroid medications really inspired me to take charge of my own health.

Today on Thyroid Pharmacists Healing Conversations podcast, I am really, really excited to have Alice McDonald, who is the OG Hashimoto's 411 founder.

Back in 2010, she founded the largest autoimmune thyroid support group and the first to focus on Hashimoto's. That group helped me take charge of my own health.

because it was a group of patients sharing their struggles and sharing, their success stories. And I know it's helped thousands of people around the world.

Alice has had over 20 years of lived experience and advocacy. She's now expanding her mission through autoimmune 411 and auto immune 4-1-one Academy, because really there aren't groups for like this for people who have autoimmune disease.

I feel like we've done a lot of work for Hashimoto's, but there's still so many of us with autoimmunity that need the support. Through her SmartPath framework, Alice equips patients and caregivers with the foundational knowledge they need to navigate the phase of healing in the proper order and confidently find their ways through the landscape of diets, practitioners, and protocols.

So, welcome to today's episode, Alys. Thank you so much for being here with us. Oh my gosh, it's truly an honor and a pleasure. Like I said, I wouldn't be the thyroid pharmacist, and I don't think I would have gotten myself into remission from Hashimoto's if not for your pioneering work and sharing all of the things that were working and not working with initially a small group of people, right, that grew into a really, really powerful movement.

Well, yes, actually, um, I have a lot of history, a whole history model in my upcoming academy, just outlining the different phases through history and how medicine came to be what it is today.

You know, to that point, I really appreciate you saying that, God, you've been such an incredible resource. But yeah, early on, it was challenging in thyroid groups because they were just really kind of parroting the mainstream narrative, just take this pill and that pill.

And I had done a lot of research on different things like candida, leaky gut, things that. still not really connecting that it was all part of the underlying root cause issues of Hashimoto's.

But I was trying to get out there and share that with the world. And it actually met with a lot of pushback and hostility at times. It was difficult, but I connected with some really great other advocates that were like-minded.

you know, the group itself is really has grown to what it is thanks to all of the volunteer moderators that have come through and just all the patients that share their feedback.

So I can't at all take full credit for that. I just kind of, you now, one day my kids were home sick from school and I decided, You know what, I'm going to create my own group now.

There's, and you I am just going put it out there and whoever is open minded to it will find me. So yeah, within a couple months, I took on some new moderators and they were, like I said, we worked as a team and everything expanded beyond that as what I call the rise of the root cause rebellion.

And you are definitely a pioneer in that regard. Thank you so much, I love it. Yeah, the Root Cause Rebels movement. I feel like when I was going through pharmacy school, it was very much focused on if you have Hashimoto's, if have hypothyroidism, do you take this one drug, right?

And I thought it's a really, really boring condition because there's just like one drag to take. And sometimes they would talk about like, oh, is if a person is elderly and they've been on it for a while, maybe you can keep them on armor.

but otherwise pretty much this is all you need to do and I was personally shocked when I got my Hashimoto's diagnosis but in some ways relieved and really was excited to get on thyroid medications and then it was like wait a minute this isn't it like I'm still having these raging antibodies I've still have all of these different symptoms I am giving the run around going to You know, dermatologist for my hair loss, cardiologist from my palpitations and gastroenterologist to my acid reflux.

And this is really how I became interested in figuring out if there was more to Kashimoto's. If there were things I could do to make myself feel better and really Part of that was looking through the patient advocates and patient experiences and patients forums and seeing what other patients were experiencing because the conventional doctors just pretty much said the same thing.

You're anxious? Well, it's not your thyroid. Go see a psychiatrist. Your hair's falling out? Probably not, your thyroid. go see your dermatologist and so on and forth.

I would love to hear more about Alice and what shaped your advocacy work and what was it for you to get a diagnosis of Hashimoto's? I had the same experience that you had.

I was brain foggy. It just wasn't feeling well, just way off.

Alice McDonald's Origin Story and Hashimoto's 411

And I knew, everyone's like, oh, you're under a lot of stress. You have little ones and you are caring for your mom and your mother-in-law and all of that.

All that's true, but still, it was way beyond. There was one day, I remember, um, driving somewhere, you know, and I'm on the highway and you, know my toddlers are in the back seat and i was like Where am I going?

Like Where my and then I started to like panic. I was literally like, oh my god Where where was I? Going? like I couldn't remember where I Was going was just like a moment and Then it came to me.

And I mean that was Just like okay. This is you. Know something is way off. So I got the diagnosis, I go the levothorax, and I was like, oh, thank God.

Now I'm going to be better and everything else. And now I actually felt worse. I didn't think that was possible at the time. I just kept researching, trying to do some cleanses.

Oh, maybe it's Candida and all this. And then I came across actually Dr. Karazian's book, as you know. I was like a

one woman marketing team once I had read that.

It just put together everything that I'd researched independently. So that was kind of like the foundation for me. Beyond that, I had started the group at that point.

And I have a local doctor friend had referred me to. She's like, you know, he's in the mainstream practice, but he is a little more functional minded.

So I went to see him and he was wonderful. He was like. Well, I'm not a functional doctor, but I don't mind how you get healthy as long as you understand it and you can speak to me.

I actually brought him the book and he read the books. If I wanted to try something or do a test, he was like, okay, why do you want to do that, Alice?

I would explain to him. He would actually converse with me, we were like a team in my healthcare. You know, it's, It's difficult to find that I was I, was very lucky.

And at one point he said, I said well let me just see if I go to the endocrinologist if there's anything further they can do. And I met a very wonderful endocrinologist, the nicest guy, you know, calls me on a Friday night with test results.

And, I told him I want to try armor thyroid and he was absolutely dead set against it. Just an absolute no. He was just like, it's a pink hormone. It's not like a Rome, whatever.

Just refuse. So I went online. I started looking for another doctor, another endocrinologist that might prescribe it. And lo and behold, there was one, two doors down in the same practice, both Yale educated.

She was like yeah, sure. You can try it, asked her for a vitamin and mineral testing, and she was, like no, you don't need to do that. There's nothing to with Hashimoto's.

Well, I'm like it doesn't. I wouldn't even know how to read the test results. She actually said that to me. I was like, well, I can interpret them. It's not that hard.

We'll figure it out. Anyway, went back to my Dr. Litwin in Danbury at the time, and he was, like I told you, we'll work together. That's how I figured, you know what?

Yeah, been told endocrinologists isn't always the best. doctor to treat it because they're just numbers readers. So that kind of, you know, all these experiences kind led me further into my advocacy and then sharing with other patients and just always connecting the dots, Yeah, it's amazing that you found somebody that was willing to work with you.

And it is also a very tricky situation. I know because a lot of people will come to my website or some of my social media pages, even my YouTube channel, and they'll say I was just diagnosed, which endocrinologist do you recommend?

And I'm sort of like, well, you know, I don't know that. You need to necessarily like there are things that an endocrinologist can help you with, doing a thyroid ultrasound, maybe getting the proper diagnosis.

But a lot of times they tell patients about things, that we know as patients and functional medicine integrative, they'll say things like diet doesn't matter when you have Hashimoto's.

We know diet makes a big difference or nutrient status or using a natural desiccated thyroid. It's very, very challenging. to, I don't ever want to criticize healthcare professionals.

I think they're brilliant, and they've gone through a lot of trouble to learn all the things that they learned. But many

times, endocrinologists tend to be more diabetes specialists than they are thyroid specialists.

And honestly, a that I've seen that have recovered and are thriving with a thyroid condition, they are usually self-empowered, self educated, and they're working with somebody like an integrative practitioner, functional medicine, or somebody that's a little bit more open-minded and willing to prescribe medications that are not the standard of care.

Now, I wanted to mention Dr. Datis Karazian. Back in 2010, I had to look up the year. His book came out. It's called, Why Do I Still Have Thyroid Symptoms When My Lab Tests Are Normal?

I'm going to link that into the show notes. But this was a really game-changing book for both health care professionals and patients because he was talking about non-medication approaches to hypothyroidism.

And this is an incredibly helpful book that I think a lot of times people in Hashimoto's 411 started to talk about, and it helped them uncover some of their autoimmune triggers.

What were some key issues on your auto-immune journey, were there things you found in that book relevant for you? Like the whole book, really. That was what inspired me to start the group.

I was sharing his book and his information in other patient groups, other thyroid groups. As I said before, it was incredible to me that it met with such pushback sometimes.

That's why I consider Hashimoto's 411 is the first patient advocate group that really focused on the need to address the underlying issues, the root causes to everything.

In my own journey, I guess I knew all the things, vitamin and mineral deficiencies. We talk about all that and we support posts and conversations and questions within the group.

It's fantastic. At the time, that was, I mean, Dr. Krausen's book, it's a hard read. it was written for other practitioners actually. I had to go through it twice myself and still went back and picked things out of it to reference.

It's just a lot, even the patient advocate groups, as wonderful as they are and it helped people to piece things together. If you're coming in knowing nothing, that in itself can also be, especially as the numbers grew, it's like, oh my God, what are they talking about?

This conversation, if you are a little more advanced, you reading a post and you understand what they're talking blood sugar issues or leaky gut, but someone coming in knowing nothing and dropping in there, they're kind of like deer in the headlights.

So that's where it was great to reference books like Dr. Karazian. But then again, that can be, as I said, a hard read. And that when you came in with the book and all of your programs, are so patient friendly, and having the experience yourself as a patient really makes all the difference.

So that's kind of fast-forwarding to about now. Like I said, it's like I've met so many people on the way, even though I haven't maybe been visible in the last many years, but coaching people one-to-one, friends, family, locally.

My husband and I were out Saturday night, and this poor woman sitting with us, she knows everything about MTHFR, methylfolate gene mutations. It's hard because I'm like, well, go here or I'll reference your book or programs to people because it's stuff that you just can't answer all in one post or one thing.

That's why I came up with the Smart Path. It is sequential, but there's so much more than that. Even like I said, the history module. brings you to the understanding of how the conventional medical system was created and how we got here with it.

And then conversely, the root cause approach, which is really just how things kind of were from the beginning,

right? Like ancient history, they treated with herbals and tinctures and things like that.

But in today's day and age, you have so much more nervous system dysregulation, stress, and all of that So it's a lot more difficult. Yeah. It's lot to unpack when you have an autoimmune condition.

A lot of times, the conventional approach tries to really simplify it and give you a band-aid. If you has Hashimoto's, here's some thyroid meds. if you rheumatoid arthritis or ulcerative colitis, you know, a drug to modify that disease.

But there are relevant triggers and there a lot of issues that could be underlying in a person's, I guess, whole body, not just the end organ and not part of the immune system that can be leading to that autoimmune imbalance.

I know for me, a really big part of my healing journey was figuring out why my immune system was out of balance, and a part that had to do with various infections.

I also had a lot of stress and some trauma that I had work through on my journey. Were there specific things that you found were a big of your healing?

Root Cause Healing and the SmartPath Framework

I always thought that stress was really one of the biggest triggers for me. I felt like my health issues started to come about after I had my kids, but I was so on the go for a few years when they were younger.

Maybe I didn't realize it as much until it got so bad, I have to address it. But yeah, I always felt it was definitely a stress trigger. I mean, even still, it's like I understand if I get too stressed or too many things going on, OK, just have to take a breath and kind of baby myself a little bit.

it's hard to juggle life these days more and more. I've come a long way with, as I said, all the things we know, Candida, or all these other under root cause underlying conditions, but also nervous system, limbic, fascia, musculoskeletal, that was always what I felt like.

That's always a lot of my pain because I carry all of the stress in the body and literally, I mean, I was getting a manicure one day and the girl was like, you know, massaging my wrist and she's like you're very tense.

I'm like really? In my wrists? Like that's not good, so come to understand that beyond all of that physical stuff, we also have to look to, what I call it in my smart path, the foundational four, because you kind of have at least to start to address those regulating systems for everything else to kind of stick.

I mean, you can layer in other things, of course, but, um, You know, have to address that stuff. Like I work in construction, right? I'm a construction accountant.

So I consider it like, the limbic system is kind like the fuse box, if you will. And the nervous system, is the electrical system. Lymphatic system as your plumbing, and if the fascia is like kind the sheetrock that's kind holding everything together, everything flows through it.

If that's all not working, that is your foundation of everything. That's kind of the start. Lately, I've been just scrolling through social media posts and you see there's so many new people on there.

They're just pushing detox protocols and everything else. I just want to scream and say, it's not wrong, but please, for God's sake, you need to make sure your detox pathways are open first.

Ask me how I know. Been there, done it. It's like you could feel a whole lot worse if you do things out of sequence. Yeah, yeah, I think sequence is really, really important.

And just to kind of reflect on what you said about chronic stress and that busyness and drive and overwhelm, one of my mentors once said, if you don't slow down, your body will do it for you.

That's very relevant for people with autoimmune disease, for Hashimoto's hypothyroidism, a lot of chronic health issues. It is essentially like a disconnection between your brain and your body where you might be pushing your And the only way that your body can communicate that is through symptoms, right?

And so a big part of healing has to do with us figuring out how to truly really treat ourselves. And sometimes that IS babying ourselves, sometimes it is slowing down and figuring take care of ourselves properly.

And that's why you can have the best doctors in the whole world. But if you don't have your own buy-in, if, you know, take charge of your health, If you're not a part of that healing journey, there's a chance that you are going to be bouncing from doctor to doctor, still struggling with your symptoms.

You mentioned that the landscape has really changed, and I've noticed this too, like I'm seeing a lot of noise out there on various topics. When I was first looking for Hashimoto's information, I would spend time On PubMed, looking at the research, I would go through practitioner trainings, and I'd go to the Hashimoto's 411 group.

There was not a lot of information on Hashimoto's at that time, where I felt like it was sort of an information desert. In this case, it's a bit of a information overload.

where you have thousands of people giving advice, perhaps on topics they shouldn't be giving, advice like bro gyms, how to lose weight. You know, when you're a woman in your 50s, and this is a 20 year old, you know you are a women in their 50's with hypothyroidism and they're telling you how you should lose weigh.

And that's just one example. So I'm curious if we can maybe Talk about that a little bit, some of the changing landscape of advocacy, niche versus foundational approaches.

Yeah. Well, as I said, it's just scrolling day to day. And of course, you have an algorithm. So you look at something on detox, and then there's a million and one detox protocols.

You're reading some of the information. It's little scary because it like, well, that's not really correct. Or like I've said it, just it out of context.

It's just out there like everybody needs to do a detox. Everybody has parasites and that may be true, but you might also have mold toxicity or heavy metal toxicity and those can be very difficult to detox and you need to be a lot more strategic when you go all in, depending how serious your symptoms are.

I think that scrolling through a couple of minutes on Instagram, a post that's put out It like oversimplifies it. And, you know, again, that's why I kind of put it in context for myself, too, and like for my daughters and patients.

Like, there's a context to things. It has to be a contacts and there is a sequence. You know again if you do jump into a detox protocol and you have gene mutation, your detox pathways are blocked or your lymphatic system is sluggish, your liver, you know, I mean, You'll feel a lot, a lots worse.

And I've seen it time and time again. I'd been through it myself. So that's why you kind of want to, shout it from the world. But I was like, let me put it down on paper, get it into, and that's how I kind of started creating the course.

It was like piecing things together for myself. Of course, we have wonderful resources like yours, but I just wanted to put in context for my self based on all the feedback I've gotten throughout my years of advocacy.

Yeah, I've definitely had some things that I have seen the hard way, or there's definitely been things I learned the harder way. I know one of them was people were talking about doing spirulina to help with detox, and that gave me a new autoimmune condition.

So, with giant papillary conjunctivitis, and then there was another person that was advocating using chelation therapy for detox that gave me like a full body rash including on every single mucus membrane and mucous membranes are on the inside so your digestive tract so imagine how fun that What else?

There were so many different things that I had gone through myself and others have gone though. I have people who perforated their colons with doing, you know, like the colon cleanses at home, DIY colon cleanse.

And it's quite scary. that it happens to a lot of people. I'm curious what kind of situations have you seen where over your last 20 plus years as a patient advocate or maybe that you've had yourself where you're like, wow, that was a lesson I really had to learn the hard way or perhaps one of the people you were helping advocate for.

Well, I mean, detox is definitely one of them, and I learned in recent years, finding out I had the gene mutation and the MTHFR and COMT mutations. I tried the methylfolate 5. didn't really work because the COMT, it's like, nope, I have to take the folinic acid, which is different than the follic-acid.

So just little nuances like that that make a huge, huge difference. As far as the landscape, like yesterday I was scrolling through a page and, you know, there's an influencer, whatever, and she's out there pushing nicotine patches, You know?

And it's like, There's some evidence now that to support how wonderful it can be. I mean, it could address a lot of things. But she's like, well, just buy any one on, download my ebook, and I'll tell you all about it there.

And then some person was like well what kind do I get? Just get any kind on Amazon. It's no, no don't do that. You want good quality products. Yes, just there's so much, there are so many little nuances like that, you know.

I've seen through myself, like when Dr. Karazin introduced, TH1 and TH2, I initially did the challenge and that was something we encouraged other people to do.

You could do the challenges at home and it can be very telling. I always seem to be on the other end of things. So whatever the norm is, so most Hashimoto's patients are TH1 dominant, I'm TH2 dominant.

Learning through him, that means you have higher antibody counts. your immune system kind of stores them up. So when you have a flare up, boom, it's like a grenade going off versus like, you know, little flares here and there.

I mean, I tested once, twice actually, the highest the lab would register was 14,000 antibodies. But I felt great at that time. And I tested half that, you know, at a couple another couple years later, and I felt a little worse at the time.

So they absolutely are very they can be very telling. But, I've seen so many people like they're feeling great. And but they are like disappointed that the antibodies didn't show.

It's like, well, it could have been different in a. Couple days, just it's nice to see them come down, but. you know, focus on how you feel too. Gauge your success by, you, know how, how and the things that you're doing to, address the underlying issues.

What are some things you learned the hard way in your 20 years as a patient advocate? I've learned the hard way that things have to be done in the proper sequence.

You need to make sure that, for instance, I jumped into detox previously where I didn't know that my detox pathways were blocked off. I hadn't done the gene mutation testing at that point.

And I felt so much worse. It sent my health back for months at the time, and I didn't understand why. Now with the feedback of all the other patients on patient groups and my own experience, it's like, yeah, really is that powerful.

You really, have to make sure that you have certain things in place before you jump into a detox protocol. Thank you so much for sharing that. I think that's very relevant for a lot of people where they might have pathways that are just not properly supported and then the toxins just recirculate instead of getting out and that can make them feel significantly worse.

There is a big controversy around iodine with patients and practitioners, some practitioners I would say, I think most of them tend to be more conservative, but what has been your experience as a patient advocate of people utilizing some high dose iodide protocols?

There are certain iodine protocols that people really find use in, and they feel much, much better. But maybe their selenium levels are up to par, things like that.

I started the iodide, it felt like someone turned on the lights. It was incredible. I just did that for, I don't know, a couple months, and then I kind of phased out of it.

And, you know at another time I tried it again and I mean it was like one of the worst flares, again, months of a setback.

Detox, Iodine, and Learning the Hard Way

So, there are certain protocols in place I guess worth noting that. Yeah, I think for sure it's like you talk about timing and sequence. If you are going to attempt iodine, there are certain things you want to get established first, like selenium levels, because if you're selinium deficient and iodide deficients, adding more iodines to the mix can actually exacerbate your symptoms.

Yeah. And that's about a lot of things, right? Certain vitamin and mineral deficiencies. You have to have certain things in place before. You don't know if they're getting to the cells or if you want to start to do some form of healing to their gut so that you're actually absorbing them.

There's so many little nuances. And that's why programs like yours and just having the foundational knowledge so they understand not to just jump into one protocol or one supplement, like, oh, I need vitamin B.

That'll help me. And it's like, I mean, i have wasted thousands and thousands on vitamins, you know, people you do out of desperation. It's, like oh, that must be the problem.

But it is having the foundational knowledge of how everything fits together. So you invest along the way and strategize your healing. I can definitely relate to having like a supplement graveyard.

So things that I've tried and did not work, I definitely related to learning things the hard way. I had colon cleansing, and I was like so ashamed of the appointment.

And I didn't even tell my husband I'm doing it, colon hydrotherapy, then that gave me like diarrhea for months after that point. There's a lot of things out there where I feel like you see something, but you might want to just do your own research and maybe talk to a few people, maybe talked to people that have been there before, just to get a good gauge of whether this latest internet trend is going to help you harm you or be a waste of your time, right?

You have a lot of experience with diets, medications, all kinds of protocols from AIP to LDN to Whole30 and BPC 157. Please share your experience. Well, in looking at like immune modulators, like I've seen, LDN, I mean, there were so many stories on Hashimoto's 411 and other forums of how miraculous it's really been for people to help them modulate their immune systems.

Personally, it made me feel worse. I can't really put my finger on it. It was very definitely like, just didn't feel right on. Felt a little bit worse, wasn't horrible, but it's just not right for me.

And I tried it on and off a few times. But I would still recommend someone to try it. I mean, of course, the evidence speaks for itself. The feedback from so many patients speaks to itself, BP 157, I'm currently taking, and no issues with that at all.

It's been great. Its reparative. So I've noted some kind of odd things with it. When I first was on it for a couple weeks, I started to notice like I had an injury on my knee.

I mean, 30 years ago, and it started to hurt again. And I was kind of like, that's strange. I kind looked up because I knew it was a reparative. Sure enough, I found research saying that, yes, it can kind as the blood vessels or blood cells start to liven up again, you can start feeling that pain.

Then it subsided after a couple of weeks. So I stuck with it. Interesting. And yeah, I've had a lot of different experiences. I been quite the guinea pig for a lotta things.

And you can share with others. So BPC 157 for people that may have not heard of it, this is a peptide. And so it can help accelerate tissue healing and recovery.

A lot of practitioners do like it for gut health. This is something that's more new and more emerging. in the autoimmune world. LDN is known as low dose naltrexone and this is actually an old repurposed drug where it was used for opioid addiction and compounding pharmacists can make it into doses of anywhere from like 0.5 to 4. 5. milligrams rather than like the 50 milligram dose and that does tend to have immune modulating effects where a person with autoimmunity various types of autoimmune conditions have been studied can actually get into remission with utilizing low dose naltrexone so their markers might improve and a lot of their symptoms.

Now you know to your point for some people it works wonders for some people doesn't do anything. And then there's others that might have adverse reactions to it.

I know in my experience about 40% of people feel better with it, I was not one of them. It kind of made me more depressed for whatever reason or just took my sparkle away.

Like I would just wake up really tired and groggy instead of feeling like energized like I normally do. one of those annoying squirrels that wakes up bright-eyed and bushy-tailed, and I would be like, oh, I just want to stay in bed.

And this is something that, again, we're all bio-individual. It's definitely worth a try to consider that. I believe the same goes for diets. Now, i know that there are various diets schools of thought.

Some people will say like everybody with an autoimmune condition should be on this diet. Other people might say you need to do these other things and I'd love to get your thoughts and experience with nutrition protocols.

Yeah, well, I mean, in Hashimoto's 411 and coming off of Dr. Karazian's, you know, research on the autoimmune protocol and Mickey Trescott and those trailblazers, there's really, we hardcore.

like kind of push that as kind the gold standard diet. And there's reasons for it. It might shorten your time, whereas if you start another diet, like I used to say, people, if they would give up gluten, they'd say well, I gave up, gluten.

I didn't feel any better. Well, your car is three parts of the engine that are broken and you only fix one, it's still not going to run right. You kind have to go all in.

The feedback is that hundreds of thousands of people found renewed health and well-being from the autoimmune protocol alone and still working on other underlying issues.

But that said, there was a lot of that reported that they found their renewed healthy well being by not going all into the AIP. I feel like those voices shouldn't be, they should be heard as well.

I know myself, I've done the autoimmune protocol and believe me, your body knows when you reintroduce a food that it doesn't like, it's a very powerful experience.

Even still with the Autoimmune Protocol, there's since been a modified that's not as all in. I haven't done a deep dive on that one. A lot of people just go Mediterranean or just eating whole foods.

I guess the point I'm trying to make is if somebody is not prepared or maybe they don't have the funds, I mean, it can be expensive to go all in on the autoimmune protocol.

But you know what? I wouldn't want that to discourage somebody from starting somewhere. So if they're not ready to go all in on AIP, then by all means, dip your toes in somewhere else that makes sense.

I mean, there's diets for histamines and gaps and all of that. Try one of those. when I'm kind of back in a slump and maybe I don't want to go all in on AIP, I just have like my own little Pinterest page and I save like AIp and Whole30 recipes and i just do like a modified of that and that kind gets me back on track because the Whole 30 is very restrictive so for people who maybe don t want completely give up sweets maybe some of the AI p protocol desserts will help them along so I think it's just the awareness of understanding the full reasons for each diet, and then they can pick and choose.

Everybody has their own self-responsibility. As long as they have the knowledge, they could make their decisions and take it from there. Yeah, I fully agree.

Nutrition can be a big part of the healing journey for so many conditions, whether it's Hashimoto's or autoimmunity. I can't really think of one where nutrition probably wouldn't be applicable.

My take has changed on it over the years. Initially, was introduced to the GAPS diet and the autoimmune paleo diet. I thought it was more about food restrictions and so on and forth, but then I really got into more of functional medicine, gut work, and gut testing.

I uncovered that I had a protozoa that was essentially causing me to be sensitive to everything. So I could have been eating ice cubes and with time I would have become sensitive those.

And I ended up noticing that about 30% of my clients had this same proto zoa and the research was showing that it made people sensitive to grains and it made them sensitive sugar and made sensitive a lot of the diets that were very much similar to an autoimmune approach or a paleo approach and new research has shown that this type of protozoa infection impacts the TH1 and TH2 and Th17 and impacts Hashimoto's autoimmunity and for me a big part of it is like don't necessarily go into it blindly, where you go so dogmatic into one direction and you just keep eliminating more foods, and it's been 10 months and, you've just gotten really deep into the diet and if the, diet hasn't helped you in a month or two, maybe three months, that's time to revisit what are some of the other things that might be out of balance.

And it could be, like you said, it can be stress in your life. It could some other kind of trigger, maybe gut health, mold exposure. Diving into that a little bit deeper, because that could actually be what's driving the autoimmunity versus, I have unfortunately seen people with a very dogmatic approach where they, again, disconnect from their bodies because they just focus on food restriction rather than on nourishing themselves.

They're blind to how the elimination diets when they're done for too long or too restrictive, but they are actually taking away from the health rather then adding to them.

And I think this can be very tricky whenever you have like just one protocol or one way or the highway, and I see that a lot with not every influencer and not ever healthcare professionals, but I'll see every now and then.

where that's kind of like, okay, this is kind dangerous space on the interwebs, where people are saying, like there's just one way to do this. And oftentimes, there are a lot of different pathways to healing, right?

And I know that, you know, would love to get your take on, the role, pros and cons of patient advocacy groups, because I feel like sometimes if you have the wrong If you have the wrong advocates in their own groups, they might just be like, everybody should do this, and everybody shouldn't do that without really considering the nuances of human health.

Yeah, that's one thing I would note.

Protocols, Diets, and Bioindividual Healing

I mean, you know, like in Hashimoto's 411, again, hardcore wanted to, push the AIP it's helped so many right but at some point, you know you have to consider is it becoming an echo chamber, because, again, it is like, well you don't want to discourage someone who is on AIp by giving them some other advice, but they are weighing things out.

You're not responsible for them, you're sharing information, your sharing feedback, but ultimately it's their decision. So give them the reasons why and then let them make their own decision, allow a little bit more of patient voices that speak to healing aside from just that one thing.

Again, I call it patient advocate groups, the good, bad, and the ugly. They can be wonderful for support and they are. But again, like we talked about earlier, it's like somebody coming in totally green.

It's discouraging. In a group like Hashimoto's 411, well over 100,000 patients, but they're not all talking at one time. a section or sector of the membership that's maybe tuned out because they just can't keep up with with the conversation.

So that what kind of pushed me to kind go beyond that. Yeah, I think there's a lot to learn from Patience coming together. I think there's such a huge value for that and getting that support or just even like validation if you're going through something that There's another person that's going though it and maybe you are not crazy, right?

Maybe there is something to it. And sometimes when you can Get together like that from across the world you could be talking to a person from Italy or Switzerland or South America and sharing some shared experiences or maybe learning about what practitioners in those countries are using or what what different triggers or paths to support patients have found.

There's a saying that there's no better detective than a mother, but I feel like a motivated patient that's struggling with a lot of symptoms, we are some darn good detectives in figuring out what's going to work and what it's not going work, and how to compare notes.

But I think it can be tricky, like you said, when some of the conversations maybe get censored or like you said, things become an echo chamber. I know during the pandemic, a lot of the Facebook health groups were censored.

So people were able to share their experiences with pretty much the word COVID, how it affected them or how we didn't affect them. in any kind of patient forums or patient experiences.

And I feel like sometimes you want to have a safe space where all conversations are welcome and you wanna make sure that people's experiences are validated and that they aren't necessarily pigeonholed into a protocol that may be worked really well for some people, but not for others, right?

Right, and then also, as we also talked about already, it's the sequence of things. What might be trending on social media, like detox and somatic healing and all that, within the group it might trending this week topics of diet or leaky gut.

But beyond that, there's other stages. Like you're having the conversations, but they're not necessarily in the sequence that they need to be. So if somebody comes in, they are like, oh, again, it's like they were so desperate for answers.

You come in like oh God, that's the problem for me. I must have candida and they check for it. To your point, you were talking about earlier, even with diet, like diets are root cause of our underlying issue for Hashimoto's and other autoimmune disease, but there's also a root clause to that, right?

So there are just layers of root causes. That's kind of the way I see it. There's a reason why you have the leaky gut to begin with. So you'd have to address that.

Otherwise, as you said, you could almost get worse, just sticking to the same diet. And not to mention that now

you're depressed. Why isn't it helping?

And now your nervous system, I mean, it's just like a domino effect. things that can happen and discourage you. It's not necessary in this day and age.

We have great resources, so we just have to put them in the proper context. Yeah, absolutely, and I know these days things like cold plunges are trending, right?

And I think there's so many people that have benefited from cold plunge. My husband loves them. He thinks that they're great. Would I recommend a cold Plunge to somebody with really low cortisol levels?

and an underactive thyroid as the first thing to do on their healing journey, like hell no. Like that is not where you need to go. You need get yourself in a warm place, get that thyroid function optimized.

We are not going there, right? It's like recommending a marathon to heal a broken leg. And so there's a lot of these different nuances to healing and sequencing, and oftentimes it helps having people who have the experience, maybe patients having some of a framework provided to you so you could really educate yourself and also a lot of times working with a health care practitioner because there are some nuances that can be missed if you're trying to navigate things yourself.

So I love your SmartPath framework and sequencing. I think this is a really big game changer. It's like a lot of times when I have worked with people, they'll be like, here's this cool trendy thing.

Should I do it? And I'm like you could probably do that in like six to 12 months. But first, let's get these other things in place. You know, I am not anti-cold plunge.

Like, think it could be great for a of people. Probably not where we start. I think these days that can be very, very overwhelming to be bombarded with so much information, with 75 different social media channels, millions and millions of influencers, some of them just reading a script, don't even know what they're talking about, just trying to create controversy.

How do you really avoid the overwhelm and cut through the noise? What would be your recommendation for that? Well, that's a huge one. I can speak to the cold plunge because I actually, a few months ago, went with a friend.

She was having some IV therapy, and they had the eye cryo therapy room. So I was like, oh yeah, let me give it a try. Bad idea. I was surprised I even stayed in for the full time, but when we got in the car and drove all the way home, it triggered a serious flare.

That's interesting. The most seasoned people are always learning new things from each other. Like you just said, with low cortisol, I'm like, yeah, that was definitely a bad idea for me, But I hadn't thought of it at the time.

I thought, oh, maybe it'll be good to kind of stimulate my immune system. No, bad, idea. The way I look at it is, is just reframing. So like, I mean, there's some really high profile people out there too.

And they're like oh, join me on this, you know, three day water fast. It's like well, for someone with blood sugar issues, like maybe that's not the best idea, ya know?

So the way look it, it's refraining like the typical health conversations that you see out their all day every day, but reframing them from the perspective of having an autoimmune disease where it like what could be hugely helpful.

Somebody that's young and doesn't have the same toxic load, maybe they can do a detox protocol and that was so life-changing for them. They want to shout it from the world, but when you have autoimmunity, you need to put things in context.

Again, it's like a different healing path, not just a one-off. I'm always taking fitness advice. I am not in my 20s

anymore. We'll just leave it at that.

But taking this advice from these beautiful 20-year-old women on how to be more fit, that doesn't resonate with me. Listen, when I was 20, I very fit too.

And I pretty much went out dancing, smoked cigarettes, and drank mojitos. That was my protocol to make that happen. I was with you, yeah. Yeah, well, youth is wasted on the young, as they say, right?

I look back, it's like I was always very tall and very, very thin. So looking back though, I I could just burn the candle on both ends. Maybe that's what kind of led up to some of the odd immunity that just kind got triggered at one point and that was that.

I mean, who knows? But I look back and I'm like, well, maybe there were some times that maybe I was a little more hyperthyroid. I can look and see the beginnings of something that I should have kind of babied myself a lot more.

But what can you do? You just have to plug along and try to recognize your trigger. So with my SmartPath, that's what I've laid out. What it is is kind of like the terrain of healing the sequence of things, and then there's also the train of resources diets practitioners and protocols is kinda like two different trains that we have to deal with there so that's kind help people with autoimmune disease to navigate.

And then there's also what I call the terrain toolkit, which is kind of like your, like for me, it's my vibration board. It's like I got I kind of splurged on a new device.

This is a Holos. It's for nervous system regulation. it runs 24-7. And I have to say that's been huge for me for someone that really feels like stress, at least currently, is under a huge underlying trigger.

That kind from the first day I put it on, it kind helped me to It kind of like it was nudging me to take full deeper breaths. I find when you get stressed and you're kind holding your breath or shallow breathing, this was one thing that's in my terrain toolkit.

Tuning forks, that another one of my favorite things. So I kind have introduced that throughout the course as well so that people can know about frequency, frequency devices.

And I give some cost projections for all these things. And people have different paths of healing or the way that they wanna go about it. Again, they can pick their diet and as long as they're picking something that really resonates with them, in this kind of crazy world of stress, I think that alone can be hugely helpful.

And then they determine if they need to dig deeper here or there, but with the full foundational like big picture understanding, at least they know how to navigate these things.

Yeah, that's super helpful. I think most people with thyroid issues, autoimmunity, there is a component of really balancing the stress response, and there's a big tie into trauma and impaired stress responses.

Some of us may present in different ways. Sometimes it's overperforming, overachieving. And we can get stuck in these patterns if we don't really do the work to unwind them.

And of course, there's all kinds of different ways to heal trauma there. I'm a big proponent of EMDR. I think that's a fantastic way to kill trauma. There's also waysto regulate your nervous system.

I have gone through, I don't know, maybe 500 sessions of neurofeedback that really helps your body to balance itself and sort of get into more of a calm state.

Patient Advocacy, Community, and New Resources

This can be a game changer. And then there's a lot of different things we can do and a lots of innovative devices

like the Polos that you just shared.

I'm going to put that in the show notes. So that's gonna be definitely something I'm going to add to my list for further exploration, something that helps to remind you to take deep breaths and to kind of get onto that fight or flight.

So really breath work. Some people, you know, some people are very much like, I want to meditate and do breath work. And then there's people that are like biohackers.

Then there are people in between. There are so many different paths to healing. I'm so excited that you're covering all of them and really educating people about what you found works in your 20 years of experience as a patient advocate.

resource for us over at autoimmune411.com. Printables are available on the website and they'll include some checklist, maybe some trackers, symptom track, mood track things like that.

And also some cards that people, if they want to print them out or they can save as a screenshot on their phone, that's what I do. And when they go to the doctor, you know, they're trying to remember what it is, They can just quickly reference it or pull it up on the website and it's there.

They could always go back there and reference the printables. Thank you so much for creating this resource. Can you tell us more about the other resources that you have just created for people with autoimmune disease and where we can find them?

Well, it'll be available through my website, autoimmune411.com, and it will be Autoimmune 411 Academy. So that'll the main course I'm starting with. And that will available for purchase.

Within it, I also include what I am calling an ecosystem. of resources like yourself, if you feel aligned. I'd love to have you share with my enrollees one of your programs, your liver reset program or anything like that.

Maybe we'll have as the autoimmune pharmacist. moving beyond Hashimoto's. I mean, really, so much of your work is relevant to anyone with an autoimmune disease, whether it be lupus or, you know, multiple sclerosis, any of them, your information is out there.

And that's what kind of led me. So much the information we're sharing, this could benefit so many other people. That's why I kind wanted to expand it beyond.

Of course, each auto immune disease has its You know, things obviously Hashimoto's is so prevalent, especially in women. There are a lot more things to know.

So I will also within the course have a Hashimoto's 411 module with more specifics. Again, my course is really meant to be a complement to a deeper dive protocol like your liver reset or things like that.

It's kind of what I consider a precursor to working with a health practitioner or diving into another course. And I think at the end of the day, my intention is it'll save people money because they have the foundational knowledge that they need to navigate all the resources to know when they should spend the money.

Instead of spending money on a You know, hundreds of dollars on a detox protocol, when they should be applying the money first to, you know. Other areas first lymphatic drainage, um, nervous system the other foundational things so.

That's amazing. Thank you so much for creating this. Which conditions would you say would be your ideal people that you think would really benefit from the Academy and from your new website?

My target audience is anyone with any autoimmune disease and caregivers, friends or family that want to support it. So again, it's not a prescriptive protocol by any means.

It's just a foundational knowledge base. So caregivers and family members could actually read through it and understand what their loved one is going through.

And, you know, from an expense point, like all the things that they may need to plan for. in the different phases of healing. And again, just having that understanding of what's really going on and how they can, it's a stress response that is part of the underlying issue.

Maybe they could help out with that. Absolutely. Are there specific conditions that you've helped as a patient advocate when once you kind of realize that autoimmune conditions are very similar?

Yeah, I mean, co-workers. I have a couple co workers with MS and I've shared different underlying conditions that they should look into. You know, all the things that I talk about.

Testing, functional testing, kind of stressing that. A few people with lupus. I personally am not diagnosed with Lupus, but I kind of presented with a lot of the symptoms.

There's no hardcore test that says, yep, you're positive. But my doctor had said, we'll just treat it as if you do. It's kind doing the same thing. You're going to follow the path to healing, the approach.

Anyone I meet with an autoimmune disease, it's kind of like the same thing. You know, if they have Hashimoto's, then it is like, okay, there is another whole bit that you need to know about, but you still need address these other things foundationally first.

Yeah, I think with Hashimoto's or any condition that affects like an organ, you need to think about, okay, what are we doing with replacing the hormones that are not being made, right?

So with how Hashimoto's we have to about thyroid hormones, how do we replace those? But I've been doing my podcast for almost a year now and I have interviewed a lot of people who are experts in different conditions.

and it's amazing how many of them talk about vitamin D levels. So relevant for Hashimoto's, so relevant just about every autoimmune condition, really relevant fertility, relevant depression and mood disorders.

There are a lot of ways that your body can break down, but the ways in which it breaks down can be quite predictable. If you know how to fix it, how did build it back up, you can get a different conditions into remission, through that process and really feel your best.

So I'm so excited that you've put together this resource to help reach so many people with autoimmune disease. We know that Hashimoto's is one of the most common one.

And I feel like there's been a bigger focus on it thanks to your advocacy work. I've been shouting from the rooftops about it, but there are other people that really need our help.

that have autoimmune conditions and they may not know that they need to focus on their gut health. They may know not that diet can be incredibly helpful on your journeys and that nutrient status.

Just a few examples and you go deeper into including nervous system in your work. So really appreciate you putting this together and creating this outreach for more people with autoimmune disease to get the healing and the help that they need.

I appreciate you doing this even with working full-time and being a patient advocate. And I know that it takes a lot of work and sometimes sacrificing our own adrenals for a short time period, know how to fix them to really help people.

and I so appreciate your heart behind this and Thank you so much. I appreciate the opportunity to come on and share it all with you. And I just want to give a huge shout out to all of the Hashimoto's 411 moderators and each

and every one that's come through and dedicated so No one can fully understand like how much of your heart and soul you put into it and you know you can I mean you really get burnt out doing it but it's very gratifying you just have to know when to step back and kind of take it on but I just wanted to make sure that It's not just me.

My dad used to call me a bull in a china shop. I want to get out there and I wanna shout it from the rooftops, but it's with the support and feedback of everyone that's been a part of it.

So I appreciate the opportunity to speak with you today. It was great. Thank you. It was my pleasure. And yes, I will second that. I think all of the people involved in the Hashimoto's 411 community as patient advocates, as their unpaid volunteers that are taking time out of their day, to take care of other people and answer their questions.

And so I would say if you are in that group, please show your appreciation to them. You don't know how many questions they're getting a day. If you're somebody that is a moderator or doing this important patient advocacy work, we love you and we hope you make sure you don t forget about yourself when you re trying to heal others.

I've been a I've been a pharmacist for a very long time now A big part of my journey has been the wounded healer journey, where I focus on helping everybody but myself.

And part my own healing has really been focusing in on taking care of myself, and so I hope that for everybody in the healing professions, in patient advocacy world, is that they do take some of that beautiful healing energy and they also put it back on themselves.

Very well said, absolutely. And patients, a lot of us, our autoimmunity has been tied to doing a lots for others and not focusing on yourself from a different bioenergetic, biophysical, psychological perspective.

That's oftentimes the paths that psychologists will notice in autoimmune patients. So something to consider as you're out there, how are you What are you doing to help yourself heal, right?

Part of it is advocating for yourself, educating yourself but also just taking that time to care and nourish yourself. So Alice, thank you so much for being here.

It's been so wonderful to see you and to connect with you, and hear about your new venture. Everybody listening, I hope that this has been healing on your healing journey.

Until next time.