Your Guide To Successful Lyme Treatment Outcomes Transcript

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Introduction to Treatment Response

Good evening, and welcome to another episode of the Healing Lyme Summit. I'm your host, Dr. Myriah Hinchey. And tonight we're going to talk about a very important topic how to know if your treatment is actually working.

Most people have heard that you tend to feel a little to a lot worse before you start to feel better when treating tick borne disease, and it's super important to be able to tell if you're having an allergic reaction to your medication.

If your treatment plan simply isn't working, or if you're having the threaded herxheimer reaction. So here to help us navigate through it all is Casey Kelley, MD.

Welcome, Dr. Kelley, Tell us a little bit about yourself and how you got into specializing in treating tick borne disease. Thanks. Thanks for having me.

Yeah, my journey is pretty personal, and I think that a lot of people get into treating Lyme due to their own health issues or that of one of their loved ones.

I was sick for about probably 15 years with multiple different diagnoses before I really got diagnosed with tick borne infections, including things like asthma and POTS and a whole bunch of fun stuff.

and in that process and journey, I started to look for it in my patients. And when you start to look for it, you can't stop looking for it because you just keep finding it.

And in that process of being able to help myself and help other people through this journey, it's just really developed my career around trying to help these chronic, complex illnesses and patients.

And I'm really enjoying the journey. That's wonderful. Yeah. When you're acting as a functional medicine doctor and you're looking for that underlying cause, it's if it's there, you.

Yeah, absolutely have to address that. So let's jump right in.

Dr. Kelleyu2019s Lyme Journey

What would you consider to be the most common indicators that a previous treatment plan did not work? So I typically go mostly by symptoms. I think Lyme and chronic infections are still mostly a clinical diagnosis.

So the labs can be very helpful. And it's worth checking them, especially if there's red flags in the history that make you want to look for it. But we still have to really, really take a good history and try to figure this out.

So if a patient has done a treatment prior to coming to see me, or if they're in the process of working with me and you know, they're not getting any better whatsoever, they are getting worse and continuing to progress.

those are big key signs that the treatment is not working. and, you know, sometimes these are subtle. Like, sometimes we we feel like we're not getting better, even though we are, because it's so subtle in our day to day lives that we don't necessarily see it.

Kind of like when you see a little baby and you only see that baby every three months. They look huge the next time you see them. But the mom thinks that they're, you know, not much different because they're seeing them every day.

So it's really important to kind of dig in and figure that out, you know. Are your symptoms better? Are they different?

Where are they. But if they are not any better whatsoever, if they are getting worse, that's always requires us to go back and take a deep dive and say, is this treatment work thing is or something?

We're missing where, where what's going on here? What what do we need to be doing to fix this? Right. And so how would you differentiate between whether a patient was feeling worse because of having a herxheimer reaction, not properly detoxifying, or if the treatment plan isn't working?

It's a great question. We get asked this all the time. First and foremost is the question I will ask back is, what have you done to try to help support your herxheimer reaction?

Is it because as a doctor, when I found these things, I the way I describe a timer is it's typically your symptoms, but worse. Or it's like the worst flu hangover you've had, you know.

And so if any of those things are kind of flaring up and some people are having those symptoms, my first question is, what have you done from our herx support handouts and information that we've given you?

because if it's a hard time, a reaction, generally speaking, one or 2 or 3 of the tricks that we have for time support will help at least take the edge off of the symptoms.

And if it can take the edge off the symptoms and make everything a little easier, that's a really telltale sign that this is a herxheimer reaction.

Signs a Treatment Plan Isnu2019t Working

We can feel a little bit better that that's probably what's going on. If they've tried a bunch of herxheimer, supportive therapies and nothing is working and they continue to get worse, that's a sign that this is not the right treatment for them.

the other signs, some other signs that we look forward to is if they, like an allergic reaction. So if this medication or if this treatment is causing a side effect.

And that's the tricky part, is trying to figure out side effect versus herxheimer reaction. So certain medications can be very hard on the gut. For example like doxy cycling can cause ulcerations in the gut mucosa.

So if someone is having acid reflux, GI symptoms it may actually be a side effect of the medication. So we have to figure that out in the history and an exam to try to see if it's an actual side effect from the medication versus a herxheimer reaction.

It's tricky. You know, a lot of there's not a perfect there's not a lab test that will tell us. Side effect versus herx or fail or versus herx. You know, so we have to really think through it and partial through it and talk it out.

Right. And on the flip side, are there signs, or milestones that you would look for to get clues that the treatment is moving in the right direction or that it is working?

So because each patient is so different and unique, I don't have set milestones that I'm looking at because some patients are going to come in so debilitated that they can't walk.

Some patients are working every day still. So it's very different. So we can't necessarily have these flags in the sand. So we have to take each patient individually.

And again it's more based on your symptoms and your symptomatology. So the ways to do that are to help figure out a really good clinical history and have a really good inquisitive provider asking the right questions to figure that out.

There are different questionnaires that you could fill out as well. Dr. Horowitz has one that said questionnaire. If the

Functional Medicine Institute has, the MS cure medical symptom questionnaire.

So there are a couple different ways out there that way as well, that you can kind of judge for yourself and periodically do and see how you're feeling that way to see if things are improving.

I do use labs. I have certain labs that I will use to try to kind of gauge what the immune system is doing, how it's responding. Those are tools, you know, that we can put together with the history to see if patients are getting better.

I also really like to ask patients what are their goals and what is better to them, because it's not good enough to just say, I want to feel better because that's different for everybody again, right?

So somebody who used to be a triathlete, you know, their goal may be that they want to be able to do another triathlon. That is not my goal. That is not what I want to be doing to make my job my health goal personally.

You know, I have some people who love reading and they really want to be able to read a book again without having to reread every sentence to try to get what's actually happening in the plot.

So being able to kind of really think through as a patient, what are the things that I can't do right now that I want to do, and how do I get there? That helps us as the providers to gauge where you are on that.

And we can also help kind of refine some of those goals and get to some earlier benchmarks for the patient individually to figure that out. And I think that's important to think about when you're through going through all of these things and you feel so horrible, like, what do I need to do, what I want to do next that I can't do right now?

And then what's the next thing that I want to do? So a couple different ways. Yeah, it's funny because I always say to patients, you know, it's important for me to document how many symptoms you have overall, what the severity is, on a scale of 1 to 10, what the frequency is on a weekly basis.

Because if you come in and you're having a terrible day, you know, you're going to tell me that you don't feel any better. And if you actually are having a good day, you know, in the symptoms of these diseases are so intermittent and all over the place, you're going to say, you're feeling so much better.

So for me, it's helpful to actually track the severity, the frequency and the sheer number of their symptoms and watch those sort of resolve over, a period of time.

Do you ever do that in your practice? Yeah, absolutely. And I you know, this is kind of what I was alluding to earlier too. So for example, like, you may feel like you're not feeling any better and let's say fatigue is one of your biggest symptoms and you still feel just as tired at the end of the day as I did before.

But when we start to dig through it, you're actually doing more in that day.

Herxheimer Reactions vs Side Effects

You're able to go to the grocery store and do laundry that day when you could barely take a shower the day before or the month before, or what have you.

And so you may feel just as tired at the end of the day as you did originally, but you're doing so much more, and that's improvement. That's improvement too.

So like, there are different ways to gauge these reactions that people have. The one caveat I will say to this, though, is there are certain people and, you know, we can all fall victim to this, where you become really obsessed almost with those symptoms.

And so we want to make sure we're monitoring them, but not be so hyper focused on them that we are missing the

forest for the trees as well. So if we're those, if we're that type of person that like, you know, can latches on to that, we've got to be able to also distance ourselves so that we can live our lives and really try to get, fulfillment and healing from this journey to and not be quite so honed in on every particular specific little tiny symptom as a part of this, because it does change so much and there's so many things going on that can take your whole day if that's what you're doing.

Thank you. Yeah, yeah. I tell people I'm like, do the evaluation when I see you every 4 to 8 weeks and try to just go on autopilot and try to live your life and focus on, you know, being positive and nurturing yourself in the time in between.

and I don't know why, but I always tell people, try to stay out of those chat groups because a lot of them can be more stress provoking than help, unfortunately.

But you had mentioned, you know, there are some tasks that you would look at to evaluate, like immune system response. what markers would you actually be looking at?

to kind of gauge some successful progress. So I look at a handful of different things really to monitor over time and look for changes, and also to look for patterns because there's certain patterns that might highlight some of the other issues going on, maybe mold versus parasites or something else.

None of the labs that I use are necessarily diagnostic of any one thing. So just because you have a low level of this or high level of that does not mean that you have Lyme, but it's a way for us to gauge all the different moving pieces, parts of the immune system, because these infections are so smart and they really do alter your immune system, which is part of why we feel so crummy when we have them.

So I look at things like the CD 57, which is a natural killer cell. I'll look at TGF beta transforming growth factor beta C for a C3 a I'll do a CBC count, which is a white, and red blood cell and let complete blood count metabolic panel looking at kidney liver functions and electrolyte panels.

and, you know, a handful of others, just kind of depending on what the symptoms may be, we can look at Epstein-Barr levels, we can look at Candida levels.

We can look at ECP, which is can be a marker of parasites or allergies. And you know, of course we'll look at Western blots and DNA testing and other things for infections along the way as well.

But I like to get a baseline when you first come in so I can see where you are. And then when I'm looking for our trends for these. And they also help kind of support different supplement support that we can give to patients too, that might help to balance the immune system and the different ways that it's off.

Those are just their tools. They're tools in your toolbox, but you can't use them as a black and white. This means that okay. Yeah. Right. As you said, it's a clinical diagnosis.

And a lot of in my opinion, you know, looking at whether the treatment is working or not working comes back to the changes in the clinical presentation.

So, yeah. okay. So what would you say are the most common pitfalls to successful treatment? It's a big mess, you know. And this is I think, where, an integrative and functional medicine approach to these is so necessary because often, especially with chronic Lyme or chronic vector borne infections, there's so many other moving pieces, parts.

It's not just one thing that's happening in the system. And so if there's a plateau and you're symptom relief, if you're not getting where we want to get, if we're not responding at all or if some of your original symptoms are better, but now you've got some new stuff showing up, we've kind of gone down a layer, if you will, in your symptoms.

We have to look at where the roadblocks and hiccups are.

Tracking Progress and Clinical Markers

And some of the big ones that show up are mold toxicity, hmhm, mast cell dysfunction. other co-infections that were missed or parasites that have been missed.

I think one of the biggest things overall, that can really hinder healing is limbic system and vagus nerve system disrepair in our brain's ability to think it's helping send out all of this constant inflammation, and it just becomes really hard to fight against that, to really heal and get better.

And there are ways to work through that and process that. But that is a big part of the journey for a lot of patients is to work through that and repair that.

That's a big, big hiccup. I think that often gets missed. Yeah I agree. What are some of your, favorite maybe just your your favorite? your favorite therapy that you like to recommend to patients to deal with that?

Yeah. So, I mean, I have a big handout with multiple different things on there because everyone is so different and I want people to start where they need to start with these things.

I generally, though, am not recommending diving right into trauma work on the first day. It's much more vagus nerve and, foundational work for the nervous system.

I think there are some really great programs out there, that will walk patients through these step by step. Primal trust is one of my favorites, but there's others out there as well.

There are, wearable devices or other devices for vagus nerve stimulation and calming. there are also, you know, binaural beats that people can listen to.

You can gargle and sing. That also helps your vagus nerve, heart rate variability, support. There's a lot of books out there, that I will recommend for people.

And I can I can go into details if you want me to, but there's so many different options and there's different ways to approach that healing that I often try to give patients a handful of options so they can see what makes sense to them, because not everyone's going to be able to start a big program from the get go.

But they could do five minutes a day of binaural beats or something a little more simple to get them started and then build upon that over time. Yeah. That's great.

let's see, are there any, in your opinion, are there any sort of risks associated with, continuing working a treatment plan that is ineffective? Well, I mean, there's definitely rest of the pocketbook if you're spending a lot of money on things and it's not, get me where you want to go.

If we're using things like prescription antibiotics, we also run the risk of really disrupting the gut, and creating dysbiosis or even C difficile infections in the gut.

If we're kind of hammering away at prescriptions that aren't working. So there definitely are pitfalls to it. There's plenty of herbs and things that are pretty safe and benign, and so it's not necessarily going to hurt you to be on it, but it was not helping you.

That's like one more pill that you have to pay for and take and swallow. Right, right. and then, you know, you can always end up with an allergic reaction or some sort of bad side effect from a treatment that's working or not working.

Right. So we do need to be very mindful and appreciate that and not miss it. Do you have any advice to a patient that might be struggling, thinking that their plan isn't working?

No. I think you have to advocate for yourself. You know, even with, Lyme literate providers who who know this, you know, you still you know your body better than anybody and you're living in it every day.

And if it doesn't feel right to you, you have to advocate for that and say, this doesn't feel like it's working. You know, this may be a hoax. You're telling me it's this or that, but this doesn't feel good.

I really want to try something different. I think that that's fair to have that conversation. You should have a partnership with your provider. And so as the patient, if you don't feel comfortable, speak up.

Yeah, absolutely. Yeah. anything else like what would be your number one tip or advice, to a patient that's new, who thinks that they have a tick borne disease or is newly diagnosed and just doesn't really know where to start?

Yeah, this goes back to your own self advocacy. Again, you really have to to look for that provider who's going to be the right person, who is willing to listen to you.

And if you meet with somebody and it doesn't feel like a good fit, you got to go somewhere else and keep looking for that person who's going to hear you and work with you to help create a treatment plan, but you need to educate yourself, and you need to really learn about what these things can do.

And, you know, if you've already kind of done enough of the research where you think that that may be what's happening, you need to find a provider who's going to test you for it and test for it with the good tests, the reliable test.

You know, even though our tests are still gray at best, sometimes, you know, being able to find the providers who can at least hone in on on the better ones that are available out there and really start to take that information and take a deep dive for you.

Common Roadblocks to Healing

Islands is where I would always start. Eye labs.org. that's where we train providers. to, to treat these infections. And so you can start there by looking for a provider who has that education in that background.

And we're all over the place. So you should be able to find someone hopefully close enough to you to at least get started. Yeah, I labs is a wonderful organization.

it is where luckily I wound up when I started this whole journey, my gosh, like 15 years ago. And, all of the providers there that are involved in the organization, itself is just, invaluable.

So islands.org I lads.org very, very valuable resource. Do you want to share maybe your top 2 or 3 favorite whether there you know prescriptions herbals self-care detox. You know what.

What is your go to when you're trying to help someone decipher, you know, whether they are feeling absolutely terrible because of purchasing or, you know, if it's just that their plan isn't working, like, how do you start?

How do you dive into that? How do you figure it out? So yeah, I have a great handout that I give to people to get and give them a roadmap, for where to go from that.

And the two kind of big caveats that I think about are one and increase and support detox, make sure you're flushing out the toxins and clearing that out. And two is lowering inflammation.

And they're pretty similar. They kind of go hand in hand. But those two, if we kind of focus on one or both of those will typically see some improvements.

I really enjoy SPM active or other SPM or specialized pro resolving mediators, that clear out inflammation that's already there. If we're working, we're probably inflamed.

So this is, from a fish oil product that will help flush out the inflammation. I also really like Berber panela, which is an herbal drop from neutral medics.

That's great for neurological purchasing. So fatigue, brain fog, irritability, mood issues, where people can take, I mean, you can take 20 drops eight times a day to help.

Really kind of calm all of that. some. I have a little detox lemonade that I also I this works great in kids, too. it is anywhere from a teaspoon to a tablespoon or so of baking soda, juice of half a lemon and then a couple drops of stevia.

And it's just, it's very alkaline and supportive, drink. And like I said, kids usually will will drink this. You can make it so that the kids will drink it, which is nice because it's hard to get pills and things in the kiddos.

but we get very acidic when rehearsing too, and this helps to alkalis the system and kind of calm things down. And it's, you know, simple stuff that we can find in our cabinet.

so, so we don't have to go buy a whole bunch of stuff. so those are just a couple little, little tips to help support purchasing. And like I said, if it takes the edge off, it may not clear up the herbs entirely.

But if it takes you from an eight to a six or 8 to 4 or, you know, we're we're making progress. Yeah. So if you have a patients that that is seeing, do you typically add in these supportive cares and have them kind of push through with their treatment protocol?

Or would you say, you are more on this side of like decreasing the dose or do you pause the treatment? because I've talked to so many practitioners that and we typically seem to fall in one or the other category where we're like, okay, suck it up, push through, get through it, you know, and do all of the supportive care or you know, we tend to like, stop, try to detox, deal with the inflammation and then move forward.

Where do you fall? Yeah, this is some of the art of medicine I fall on. you know, I'm okay with you being uncomfortable, I guess. And I was like, okay, is not even the right word, but, you know, I can deal with uncomfortable.

I can deal with manageable. But if it's so unmanageable that you cannot get out of bed, you cannot function, you cannot live your life. That's too much. Yeah.

Supportive Therapies for Herxing

that can often for me as a provider, create more of a mess for me to pick up and clean up afterwards. to try to put everything back together, that I don't find it worth it to go quite that push, quite that hard.

So, that's where I find herbal treatments are sometimes beneficial because you can kind of tailor that much easier to the patient. You can increase slower, you can kind of stop a little bit, you know, you can go a little more at their pace versus antibiotics, which are, you know, most of the time, here's your dose.

Good luck. Right. It's like you can't have cancer. The dose of any antibiotic. Yeah I tend to fall in the same, same campus. You with the kind of like, you know, as long as you can function, get through it.

and it's funny, until I was putting together a talk on, like the the physiology of a Harkes, you know, I kind of just was like, you know, it's okay. It's a temporary worsening.

You know, you feel worse, push through. And then when I started looking at, like, chemically, biochemically, what a Harkes actually does and is in the body, I was like, oh, wow.

Like, we're really pushing like, all of those inflammatory cytokines and the body becomes so overburdened with toxins. And I was like, wow. I mean, if if someone doesn't turn around, in my opinion, within a couple days, I'm

really starting to pump the brakes, which is something that for like a decade I didn't do because I was like, wow.

Like I'm actually increasing inflammation, toxicity, oxidative stress, which from my own theory is making the patient, you know, more hospitable and actually feeding the infection.

So it's just so funny, right? Like the longer you practice and the more you learn like, the more you learn. Yeah. So, yeah. Yeah, but I've always been one of those as long as you can handle it, like suck it up and push through.

So it's just, it's interesting, but I love all of the therapies, that that you mentioned. Yeah. And those are just a handful. I mean, there's so many different ones too.

And what works for one person may not work for another person. That doesn't necessarily mean it's not a hurts, just means you have to find the right tool to help you get through stuff and help your symptoms. Right.

And I think, you know, from, Doctor Horowitz. Right. Like the main component are supporting detox, dealing with the inflammatory cytokines cascade and alkaline izing the body. Right.

Those are the big three components. obviously, usually. One or all three. Yeah. We'll do we'll help take that edge off. but yeah, I agree that, you know, and we've learned so much too is is a, it's a world as a whole with the cytokine storm thanks to this and pandemic that we all just went and.

Yeah, but it it's been like as you know as Lyme docs, we've known this for a long time and that's what this is. And so we have to manage it and yeah do it in a way that isn't going to create more problems.

As and God forbid, the spike protein, whether it's, you know, from the vaccine or from getting Covid. That to me, you know, is just like throwing a whole stick of dynamite into the whole, you know, tick borne disease and infections.

it just really exacerbates things for quite some time. I see in almost every single patient. Oh yeah, it can. And and it's highlighted patients who didn't know they had tick borne infections.

Yeah. That's where we're finding a lot of them, you know post-Covid you know and now they're positive for vector borne infections because it was just hiding under the surface.

Yeah I had a really interesting, talk with doctor Bill Rawls last night actually, about all of these dormant microbes in the body and how, you know, something comes along and it's like the straw that breaks the camel's back.

And then all these microbes that were being controlled by the immune system just go on this feeding frenzy and you know, when that's it, you have like, this full blown, onslaught of symptoms.

Now it's exactly. Yeah. And that's what we're seeing with a lot of our long hauler patients. I literally have one long hauler patient who did not test positive for a vector borne infection.

Wow. One. Wow. That's kind of. You know, want to repeat that testing just to confirm. Yeah. These negative. Oh. So, Casey, anything that you would like to have our listeners hear or share with our listeners before we conclude our interview today.

I think one of the most important things to remember, especially even if we're, you know, just Lyme in general, but talking about to is it's working. It's it's not working.

Where where am I with this is to really remember that these are marathon treatments. This is not a sprint. If this were so easy where I could just give you two weeks of a medication and be done with it, my my life would be so much easier.

Oh yeah.

When to Push Through or Pause Treatment

You know, but it's not that there's so many layers to this, especially if you've been sick for a long time, that we really have to be able to spend time to get through that in the patience aspect of it is really difficult and it's difficult from the patient aspect, but also the provider.

We want to get you better as soon as possible to, you know, it's not easy for us as the provider when things are moving slow. We we we're on your you even when we're we want things to move faster too.

But sometimes we can't go faster for multiple reasons or there's all these hidden roadblocks that we have to uncover. So I think the important thing to look at is to, you know, look at those small goals and, and work your way through that and give yourself grace as you're going through this process and appreciate the wins and appreciate the victories that you are getting and being able to look back and be like, I couldn't have done that last year.

This is better. You know, we're working through this. That's we sometimes have to remind ourselves of that because we're not where we want to be or we're not better, you know.

But we are. And it's that, that reminder to get through that process. in our practice, we actually have a disco ball. When people get their lives back, we have a disco ball from the ceiling.

We put on some disco music, we take pictures, they get a disco ball, we get to like, put a pin on the map and a disco ball because we really have to celebrate those victories and those wins when people really start to be able to get their life back.

And that doesn't necessarily mean that they're perfect or they're in remission or the labs or are normal, but they're able to do the things they want to do again.

And they they've gotten their life back. And that is huge. And you know, these these chronic infections are our daily reminder that we take care of ourselves.

We have to eat well. We have to sleep well. We have to stress well, right. and, you know, don't let it be a bad identity. Let it be a good identity. Like, yeah, you know, I am a survivor of these infections.

They're probably still in me. We've made peace. We're buddies. We're friends now. Everything is great. Like we're going to move on and, like, go on and enjoy our life.

Patient Advocacy and Finding the Right Provider

But you can take a really long time to get to that spot, and that's okay. Give it a time. Let your body work through it and and really appreciate love your system and your immune system, your body for what it's doing for you.

That is amazing advice and very, very much needed. I think everybody suffering from these infections needs to hear that. Thank you so much for everything that you do.

Oh well, you know, I'm like I said, I'm a survivor myself. I've been through this. And I think that that helps me connect with patients and understand where they are.

I've been afraid to stand up because I was afraid I'd pass out, with it. But you can come a long way, and it just you just have to keep putting one foot in front of the other.

And that's really my blessing and my joy to be able to help people get to their disco ball. Yeah. That's awesome. So remind people how and where they can find you.

Yes. I found a Case Integrative Health. in 2019, you can find us at Caseintegrativehealth.com We're located in Chicago, Illinois. and actually in Hinsdale, Illinois as well.

We have multiple locations, so reach out to us. You can give us a call. You can set up a discovery call through our website, which is free to see if we're a good fit for you.

check us out on Instagram and Facebook as well on social media. See what we're up to and we would love to hear from you. Thank you so much.