About My Guest

My guest for this episode is Dr. Dan Kinderlehrer. Daniel A. Kinderlehrer, MD is a nationally recognized physician with expertise in the fields of nutrition, allergy, environmental medicine, Lyme disease and the healing of mind-body-spirit as a unified whole. Dr. Kinderlehrer co-founded The New England Center for Holistic Medicine in Newbury, MA and has taught extensively, including practitioner training courses at the Omega Institute, The National Institute of Behavioral Medicine, and the International Lyme and Associated Diseases Society. He created and organized the Lyme Fundamentals course which is presented annually at the International Lyme and Associated Diseases conferences. He is the author of several review articles in medical journals and the Lyme Times. His integrated medical practice in Denver, CO focuses on the diagnosis and treatment of tick-borne disease. Dr. Kinderlehrer is the author of Recovery From Lyme: The Integrative Medicine Guide to the Diagnosis and Treatment of Tick-Borne Illness which will be released in 2020.

Key Takeaways

- Is Disulfiram a game changer in the treatment of Lyme disease?
- Where did Disulfiram originate, and what has it historically been used for?
- Does Disulfiram potentially eradicate Borrelia and Babesia?
- What is the role of Disulfiram in the treatment of Bartonella?
- How is Disulfiram dosing managed to minimize side effects?
- What foods, personal care products, supplements, and medications need to be avoided while on Disulfiram?
- Can Disulfiram be used in those with sulfa drug sensitivities?
- Do some patients need Disulfiram long-term?
- Can Disulfiram be used in pregnancy and in children?
- What is the role of copper in terms of side effects with the use of Disulfiram?
- What are some of the mental health side effects observed with Disulfiram?
- Does Disulfiram negatively impact our healthy microbiome?

Interview Date

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Transcript

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[00:00:01.13] *Welcome to BetterHealthGuy Blogcasts, empowering your better health. And now, here's Scott, your Better Health Guy.*

[00:00:14.04] *The content of this show is for informational purposes only and is not intended to diagnose treat or cure any illness or medical condition. Nothing in today's discussion is meant to serve as medical advice, or as information to facilitate self-treatment. As always, please discuss any potential health-related decisions with your own personal medical authority.*

[00:00:34.29] Scott: Hello everyone, and welcome to episode number 111 of the BetterHealthGuy Blogcast series. Today's guest is Dr. Dan Kinderlehrer, and the topic of the show is Disulfiram. Dr. Dan Kinderlehrer is a nationally recognized physician with expertise in the fields of nutrition, allergy, environmental medicine, Lyme disease, and the healing of mind, body, spirit as a unified whole.

Dr. Kinderlehrer co-founded the New England Center for Holistic Medicine in Newbury, Massachusetts, and has taught extensively including practitioner training courses at the Omega Institute, the National Institute of Behavioral Medicine, and the International Lyme and Associated Diseases Society. He created and organized the Lyme Fundamentals course, which is presented annually at the International Lyme and Associated Diseases conferences.

He is the author of several review articles in medical journals and the Lyme Times. His integrative medical practice in Denver, Colorado focuses on the diagnosis and treatment of tick-borne diseases. Dr. Kinderlehrer is the author of Recovery From Lyme: The Integrative Medicine Guide to the Diagnosis and Treatment of Tick-Borne Illness which will be released in 2020. And now, my interview with Dr. Dan Kinderlehrer.

[00:01:57.00] Scott: I want to be clear that my intent in doing this show is really not to promote the use of Disulfiram, but rather to share information about this potentially exciting new therapy so that you the listener can have a dialogue with your doctor about whether or not this may be something that may be helpful for you. It is a hopeful time, and Disulfiram represents a very exciting new opportunity.

But that does not mean that it's right for everyone, or that it's without potential side effects. Dr. Dan Kinderlehrer has been practicing medicine for over four decades and is one of the early practitioners with a focus on helping those with Lyme disease. Very honored to have him on the show to share his knowledge of Disulfiram with us today, thanks so much for being here today.

[00:02:36.12] Dr. Dan K.: You're very welcome.

[00:02:38.14] Scott: So let's talk about how you personally became interested in Lyme disease, the work that you do today with your patients. Did you have your own personal health journey with Lyme disease that gave you the passion you have for the work you do today? And have you had any personal experience with Disulfiram?

[00:02:55.11] Dr. Dan K.: 1996, I became acutely ill in August. Basically, the sudden onset of high fever, shaking chills, night sweats, and that led to a diagnosis of Lyme within a few weeks we figured out it was Lyme. But we had no idea that I had Babesia, which was barely on the radar at that time. So even though I was on prolonged antibiotics, I continued to be ill. And that led to my interest in Lyme disease when I finally got better from that, which was really quite prolonged. Because at one point, I was re-infected and had Bartonella as well.

And I decided to dedicate my practice the treating people with tick-borne infections because it was clear that the internist, the infectious disease people had no idea what was happening. One of the things that I would tell patients is ten years ago; now, this would go back 20 years, right? Ten years ago if you went to the infectious disease doctor and said I think I have Chronic Fatigue Syndrome, they say look there's no such thing as Chronic Fatigue Syndrome, you're depressed, and they'll send you to psychiatrists. Then patients would go to the infectious disease doctor and say I think I have chronic Lyme, and they'd say there's no such thing as chronic Lyme, you have Chronic Fatigue Syndrome, and times have changed, right?

[00:04:25.16] Scott: Yes.

[00:04:26.04] Dr. Dan K.: But back then, most of us who were involved with diagnosing and treating people with chronic tick-borne illness, we ourselves or family members were involved, we were sick. I lived in Massachusetts, and all three of my daughter's got Lyme disease, my ex-wife got Lyme disease. This is a really common occurrence; well definitely over the past two decades. So that's how I became interested in Lyme disease. Now I had a really strong background, I mean, first of all, I'm boarded in internal medicine.

But I never practiced as an internist per se, I was always interested in looking at people from a more holistic viewpoint, and back then, they, in fact, called us holistic doctors as you know the nomenclature has changed. But because of that interest in preventive medicine and nutrition, I started seeing people with all sorts of environmental sensitivities, and I became an expert in environmental medicine. And also looking at the psychological and spiritual aspects of why we get sick and how we can heal. These are all things that I've studied quite rigorously before I got Lyme disease.

[00:05:48.13] Scott: So in your own recovery journey, has Disulfiram been a tool that you've personally used or were you already largely recovered before we stumbled into the benefits of Disulfiram?

[00:06:00.04] Dr. Dan K.: I would say that compared to how sick I was at my worst, I'm ninety percent. I'm really good, and of course, it's hard to compare because I'm also 20 years older than when I became ill. So I'm doing well. I'm happy to describe that.

But I have tried Disulfiram, and you might want to get into this later, but I was doing quite well until I became toxic on what turned out to be too high a dose of Disulfiram. And I had first-hand information on Disulfiram and neuropathic toxicity. So I've learned a lot about Disulfiram, I'm glad I was the first one of my patient population to have that experience because now I can recognize it readily among my patients.

[00:06:58.08] Scott: Absolutely. So my understanding is that Disulfiram in the realm of Lyme disease was first really talked about or identified by Dr. Jayakumar Rajadas at Stanford about almost five years ago in 2015 now. That was through work supported by the Bay Area Lyme Foundation; I believe there's additional work happening at Northeastern with Dr. Kim Lewis trying to continue to find tools to support those of us that have dealt with or are dealing with Lyme disease.

Do you think that we're at a point now with research, and with some of these tools that there is really the potential to completely change the game and have more hope and optimism in terms of being able to get patients their lives back?

[00:07:39.22] Dr. Dan K.: As far as I'm concerned, the game has changed. I mean, as you've pointed out, I've been practicing with practice dedicated to tick-borne illness for about 20 years. And slowly expanding the umbrella of what we can use to treat, but also expanding our awareness of the comorbidities and so on, so we've just learned a lot. And on the other hand, since I've started using Disulfiram, my practice has changed; it's been a game-changer for sure.

[00:08:17.29] Scott: My understanding is that a patient of Dr. Liegner first approached him wanting to use Disulfiram for his own Lyme disease. Dr. Liegner later documented three cases with very promising results. How did you first get interested in Disulfiram? How long have you used it in your practice? About how many patients do you have on it? And what are some of your observations in terms of its potential?

[00:08:41.06] Dr. Dan K.: Well, when Ken started describing his experience with Disulfiram in the ILADS email listserv, that's when I became aware of it. And so sometime in early 2019, I had long discussions with Ken. Ken, of whom I really respect as someone who rigorously looks at the literature as their safety-conscious, careful, and he told me the story. And that first patient that you referenced, it has been two and a half years now since he has been asymptomatic and off all treatment. And he had been eight to nine years on triple antimicrobial therapy in which he couldn't stop because he would always relapse.

So I started treating patients, first patients were the end of March of 2019; I was away most of April and slowly started putting more and more people on the Disulfiram. I now have over 100 patients on Disulfiram, so we have a lot of experience at this point.

[00:09:56.02] Scott: So let's go back a little bit to the history of Disulfiram. I think maybe listeners aren't familiar with the fact that this drug has actually been around for many decades. So talk to us a little about Disulfiram, also known as Antabuse. What has it been used for historically? What's its track record been outside of the Lyme arena? And where did it come from?

[00:10:17.25] Dr. Dan K.: Well, it's a very interesting sort of serendipitous experience with Disulfiram, which is basically it's a compound that was used in the vulcanization of rubber. When I read that I had to look up, well, what's vulcanization? It turns out they harden the rubber; I presume to make tires and other things. And the workers in those assembly plants became intolerant to alcohol. So that's how the drug was discovered, and it's been used mostly in the alcoholic population as a disincentive, as it inhibits the breakdown of acetaldehyde, which is the metabolic byproducts of alcohol, which is largely responsible for the hangover.

And I really don't know how much of a deterrent it is or was; I don't know how successful it is in treating alcoholics. But I can tell you even when I was a medical student, and as you mentioned, it's been over four decades, I'd hate to admit that. And so even as a medical student, I was prescribing this stuff. It really hasn't been used for much else up until relatively recently, although there are reports in the literature. For example, in 1972, some doctors said well given the chemical structure of Disulfiram, maybe it would be effective against malaria, and sure enough in the laboratory, it was. There are studies that suggested its in again in the laboratory,

effective against mycobacteria effective against at least one fungus Aspergillus, but probably it will kill other fungi, it is one report of scabies.

These are all just reports; there are no clinical studies. And what else? Oh, this is really interesting, HIV. It turns out that Disulfiram has the capacity to take viruses out of their latent phase, so they're no longer dormant, and somehow, that makes them more accessible to the antiretroviral drugs. And what I've noticed in some of my patients, they said I have oral herpes, and when I'm taking the Disulfiram, I start to get a little breakout and then it goes away. And then a month later, I start to get a little breakout, and it goes away. It would be really interesting to do is study, as you know we never get rid of herpes right; it just goes dormant or active. It'll be interesting to do a study with the same strategy as they're treating HIV; in other words, give people Disulfiram and then hit them hard with an anti-herpetic drug. And anyway, those have been the primary uses of Disulfiram, up until Dr. Rajadas' study, which really has been a breakthrough.

[00:13:28.17] Scott: So my understanding is that it seems to be helpful for Borrelia, its sounds like you mentioned malaria, Babesia being a cousin of malaria. That there is some excitement about its use in Babesia. Do we think that with Borrelia and Babesia that these organisms are potentially completely eradicated from the body? What do you think is happening when we're using Disulfiram in terms of the persistence of these organisms?

[00:13:53.10] Dr. Dan K.: Interesting question. We don't use the word cure because we don't have a parameter we can measure that says no cure versus cure. We can't at this point culture, and if we did, how accurate is the culture. So the terminology that we're using, and I know Dr. Liegner is using the same terminology, is sustained remission.

What I believe is more likely than not, we are actually eradicating Borellia and Babesia. And I say that simply because patients who have been on triple antibiotics who continually relapse as soon as those antibiotics are stopped have stayed in remission for six months or longer after treatment with Disulfiram. Clinically they appear to be cured, even though we can't say absolutely these bacteria are eradicated.

[00:14:57.05] Scott: And what's your clinical observation relative to Disulfiram and Bartonella?

[00:15:02.23] Dr. Dan K.: That's interesting. Initially, when I talked to Ken, he said, well, I don't think it's hitting Bartonella. But then not long after I started using it, a patient emailed me and said, whoa, I got a big-time Herxheimer reaction, and one of her symptoms was swollen glands. I said swollen glands? That's not generally Lyme or Babesia, that sounds like Bartonella, and she said oh yes, this is a Bartonella Herx, which opened my eyes. And she, of course, was on a Facebook group, I'm not on Facebook, but I get all these reports from my patients who are on Facebook. And I said, what do the people in the Facebook group said? Oh yes, they think it's hitting Bartonella.

I had a personal experience myself that it is definitely hitting Bartonella; that said, it does not seem to be eradicating Bartonella. So what happens is I see Bartonella Herxes, I have to start taking people off of anti-Bartonella drugs. And they become asymptomatic as they are on therapy with Disulfiram, but after we stop the Disulfiram after three or four weeks, some patients say oh, I'm getting some symptoms back they feel like the Bartonella, and then we might add Rifampin or whatever. But that's my clinical experience that it hits Bartonella, but it doesn't do as good a job, it's not as successful as it is against Lyme and Babesia.

I have no idea what it does for Mycoplasma, which is obviously a major player, and I suspect it's very powerful against Tick-Borne Relapsing Fever only because those bacteria really seem to have the same susceptibilities as Lyme Borrelia. And as far as Anaplasma goes, I really don't know. I don't have very many patients, I mean I have a bunch of patients, but low compared to Lyme, Babesia, Bartonella, Mycoplasma.

[00:17:08.07] Scott: So did I understand you correctly that when you're treating someone with Disulfiram, you generally are not concurrently aggressively treating Bartonella?

[00:17:16.29] Dr. Dan K.: Okay. So there are two scenarios: one is an existing patient. The existing patient might be on two, occasionally three antibiotics. I really try to use as little pharmacology as I can. Often the multiple antimicrobial herbs and they are often doing quite well. And as I put them on Disulfiram and increase the dose, I slowly take away those other antimicrobials. My experience is they will Herx a lot more if they're on those other antimicrobials.

So I'm slowly increasing the dose of Disulfiram, I'm slowly dropping these other antimicrobials, and it seems to work well. I have an experience where say okay time to stop your Mepron, a week later, oh no, my Babesia is active; I'm getting my night sweats back and so on. So I say okay, go back on the Mepron half dose, and that works. And then as they step up quarter dose as they step up the Dsulfiram, we can stop it.

So that's one scenario, another scenario is brand new patients who are not on antimicrobials. I actually don't have that many patients who fit that category, because sadly I'm not in a position to take a lot of new patients at this point in my career. In those patients, I start with only Disulfiram; I know it's going to hit Lyme, Babesia, and Bartonella even though I'm not certain of the other co-infections. And follow it, let's see what happens, and depending on what happens, I might add something. But more likely than that, I'm just going to keep on increasing that Disulfiram to see where we go and as you know, it's all individualized; everyone is different.

[00:19:18.25] Scott: In the Borrelia realm over the past few years, there's been a lot of talk of persisters, there are various protocols with Dapsone and others for hitting these persisters. Are we finding that Disulfiram addresses the persisters such that we don't really need to combine it with something like Dapsone?

[00:19:37.27] Dr. Dan K.: Yes, good question. People sometimes don't understand what a persister is versus a resistant bacteria. Resistant bacteria will grow in the face of the antibiotic; persister is dormant regardless if you're on the antibiotic or not on the antibiotic until something happens in which it becomes activated.

And Dr. Lewis made the point in the lecture that ground zero patient that very first patient saw the lecture by Kim Lewis, this was in October of 2016, and the conference in Mount Sinai. And he said, I mean I'll come close so describing with Kim Lewis said, when he tested Disulfiram against Lyme in the laboratory and then measured to see what was left, he said it was sterile - no persisters, they were stunned. And that seemed to be our clinical experience, giving that we're seeing prolonged remissions.

[00:20:44.22] Scott: What are your thoughts around Disulfiram crossing into the blood-brain barrier to address infections there. Sometimes we think of Babesia being in bone marrow, for example, are there any kind of protected sites from Disulfiram's potential ability to really address these organisms?

[00:21:04.01] Dr. Dan K.: There is definitely evidence that Disulfiram can cross the blood-brain barrier. Although, I want to be clear that I think most of the problems we see in the brain are caused by neuroinflammation, not direct invasion by microbes. In fact, in the old days, we would treat people with antibiotics that didn't cross the blood-brain barrier, and yet central nervous symptoms improved; which is consistent that most of these problems are from neuro inflammation, that said Dr. Rajadas believes that Disulfiram actually decreases neuroinflammation.

And he has a report from just last year about different inflammatory parameters decreasing in mice treated with Disulfiram, but I'm wondering whether that's secondary to decreasing the microbial population. So I really don't know if it has a direct effect or not, perhaps it does. Yes, in terms of bone marrow, I've actually done a little research on that; we know that acetaldehyde affects the bone marrow, which, as you know, is the primary metabolite of alcohol. I don't know if Disulfiram accesses bone marrow, but I'm impressed that Disulfiram accesses a whole lot of extracellular spaces. So I would suspect more likely than not, but no data on it.

[00:22:39.18] Scott: One of our listeners asked if you've had any experience using Disulfiram in patients with Morgellons? And it's an interesting question because I know at the ILADS conference we both were just there recently. Eboni Cornish spoke on Morgellons, and one of the tones of her message was treating Morgellons really is similar or the same to treating Lyme disease, that you really have to focus on Lyme and co-infections in these patients. But any insights or thoughts on Disulfiram in the Morgellons population?

[00:23:11.12] Dr. Dan K.: No, unfortunately, I can't add to what Eboni said. Certainly, I agree with what she said that generally, you really do need to treat Lyme and co-infections, and use various vermicides, and so on. But I do not have any experience on Disulfiram.

[00:23:30.17] Scott: Do we know exactly how Disulfiram kills Borrelia and Babesia? Can you talk to us a little about the dehydrogenase enzyme? The acetaldehyde that you mentioned. What is the actual mechanism of action with Disulfiram against these various pathogens?

[00:23:49.01] Dr. Dan K.: Yes, I can answer that easily. We have no idea. I mean we know about toxicity in terms of antimicrobial pathophysiology, we really don't know at this point, we really don't know.

[00:24:06.07] Scott: Which is why it's interesting that research is happening like Dr. Rajadas where they looked at so many different agents not necessarily even anticipating why they might or might not work, right? I think they screened several hundred agents in some of that research as I understand.

And thus, identified Disulfiram as being potentially helpful. Let's talk a little bit about how you use Disulfiram, so how do you approach dosing it? What has your patient experience taught you about kind of the ideal dosing strategy to balance effectiveness with tolerance?

[00:24:40.17] Dr. Dan K.: Okay. So I'll just mention that using a technique called high-throughput screening what Dr. Rajadas did was his laboratory he screens something like 4,336 compounds against Borrelia burgdorferi. And then in 2016, they published their top 20 hits and number one out of the top 20 was Disulfiram, very impressive. And he had reasons to suspect this may be effective because he's brilliantly put the biochemistry together. In terms of how I implement, it was interesting, and I remember talking with Dr. Liegner in the early days of using Disulfiram, and I said, wow, you start on 500 milligrams a day.

This is what he did with his first three patients that was reported in that article you referenced. And he said well yes, I don't do that anymore, he said. He said I usually start people on 125 every three days at this point. And he pointed out that those first three patients were all well over 200 pounds. And they were already treated with a lot of antimicrobials, suggesting that their microbial load would be low. And anyway when he said well I'm going to start a 125 every three days, I said okay I think I'm going to start my patients on 62.5 every three days because I have a very sensitive population.

Just reading about Dr. Liegner's patients, I realized that his patients are not a sensitive as mine or as fragile, at least the ones he reported. So I started off giving people 62.5 every three days, and then I found oh that's a little too much for some people in terms of Herxheimer reactions, not toxicity. So then I became more aware of that population, and many patients now I start on 31.25 every three days. But I have patients who are so fragile, and I so don't want to risk Herxheimer reaction whose not only will cause systemic inflammation as you're aware, but set them back and perhaps make them more sensitive in the future to using this drug and might prescribe somewhere between ten and twenty-five milligrams in an enteric-coated capsule time-released once a week, and if they tolerate that and say okay now you can take it every five days and so on.

So I start people on a low dose hoping that they'll tolerate it, and by tolerate it, I mean they will not have a severe Herx, but a mild Herx is fine. I would say the most common Herx reaction that the population would simply be fatigue. And the fatigue lasts a week, and then the second week they're actually back to baseline, and after two weeks they check-in and report and then I was like okay, instead of every three days now to go to every two days. They have to check in every two weeks, that's the deal. And sometimes they're doing well, and they want to go quicker, and I pull the range, and I said no, you really don't want to do that.

I have patients who said just put me on the full dose, let's get over this, and that's a really, really bad idea. In fact, my patients are describing to me what is happening with reports on Facebook. In which there's a lot of neuropathy and other aspects of neurotoxicity, and they're describing that these patients are typically starting on higher doses, they're progressing the dose too fast, and they're staying on a toxic dose even though they're toxic, even though they're having encephalopathic symptoms. There's a patient in Ireland who's communicated with me, who's been treated by a well-known Lyme doc who rapidly progressed her from 125 daily to 500 milligrams a day, and she's having severe side effects.

And this doctor said it's just a Herx just keep doing it, keep doing it well she's totally disabled, she's in bed severe neuropathies, severe cognitive impairment, and so on, and it's very sad. And what I tell patients is tortoise beats the hare, please be patient, we're going to start low; we're going to go slow. We never increase the dose more frequently than every two days. If you have a significant Herx when that stops you from functioning, we're going to back off on that dose and go to a lower dose.

[00:29:50.18] Scott: So, what is the ultimate dose that you find on average is needed to get to in order to achieve this sustained remission? And what's the general duration of Disulfiram therapy before it's entirely stopped?

[00:30:04.24] Dr. Dan K.: So we have guidelines based on weight. The original guidelines proposed by Dr. Liegner, we've actually brought it down, so we're using lower doses than he originally suggested. And I think we got thrown off a bit by those recommendations because his first patients were over 200 pounds and they tolerated quite high doses. At this point, I would say the average dose is 250 milligrams. My average patient weighs somewhere between 115 and 150 pounds, and again the average dose would be 250 milligrams daily, but not for everybody.

And on the lower end, it might be less, so people between 100-125 it may not be 250 milligrams, and at the higher end, we might bump it say to 250 milligrams alternating with 375 milligrams every other day. We have these weight recommendations, but as you know, everyone is different metabolically, particularly in their detox profiles and capacity. So we're very careful, and as you know, we're particularly on the lookout for neurotoxicity. I don't see nearly as much neuropathy as my patients describe that they're reading about on Facebook.

I do see some neuropathy in particularly that would be pins and needles sensation and numbness and so on. What I do start to see at the higher doses meaning higher for that patient, so, for example, someone weighs 140-150, and we say well let's try going from 250 milligrams to 250 alternating with 375. And they immediately report oh I really have some brain fog and I'm depressed, at which point I will advise the patient stop the Disulfiram, get back to me in two days and what they report is after 24 hours they feel great, less than 24 hours they feel great.

That's clearly a drug reaction, that's not a Herx reaction. A Herx reaction we'd be able to recognize as what a Herx reaction look like prior to that. My own experience with Disulfiram toxicity to my brain has really educated me on what to look for in patients. Initially, I had difficulty discerning the difference between a Herxheimer and Disulfiram toxicity, but now I think I've gotten quite good at it. And the caution to patients is you have these problems; you let me know right away. Do not try to ride them out; do not try to push through.

And if I'm even remotely suspicious of an encephalopathic symptom like the brain fog or like depression or other mood changes, I will immediately stop the drug. If we do that and it's a drug reaction, they get better immediately. The people who don't get better immediately are the people who continue at a dose which is too high for them in which they are experiencing toxicity from the drug, and the longer they stay on it at a toxic dose, the harder it is for them to recover, it can take quite a while.

[00:33:30.25] Scott: So it sounds like the half-life of Disulfiram is not incredible long if they're seeing getting back to their baseline within a couple of days. Is that true? Do we know what the half-life is?

[00:33:42.02] Dr. Dan K.: That's a great question. Because if you google what's the half-life of Disulfiram, it'll say 60 plus hours. Whoa, that's a long half-life; it takes days for half of it to be removed. But Dr. Rajadas has sent me some data that suggests the half-life is more like eight hours, and clinically I think it is much shorter because when we split the dose, people do better. So I always have people splitting the dose, unless they're so low you can't split it anymore.

So, for example, if they're on 62.5 daily, I'll split it to 31.25 twice a day. And also the metabolites have half-life according to the data that Dr. Rajadas sent me of say ten hours plus or minus two or three hours, but that doesn't mean there might not be cumulative toxicity if you are chronically exposed to those metabolites, and these toxic symptoms won't go away immediately because we've done some damage.

[00:34:54.15] Scott: So once you get a patient up to a reasonable dose of Disulfiram, kind of towards your target dose, what then is the duration of Disulfiram before you say okay we're done, you should now potentially have a sustained remission?

[00:35:10.04] Dr. Dan K.: I'm leaving people on their target dose usually about ten weeks or three months, I would say on average, on average, that's what I'm leaving people on. Dr. Liegner's made the point that many people don't necessarily feel well on that target dose, but after they stopped the Disulfiram, they improved significantly. My experience thus far and I haven't been treating people as long as Dr. Liegner, although it appears I have a lot more patients on it than he does.

But he's also seeing more patients who finished the course. And I'm definitely seeing patients stop the Disulfiram and then said oh yes this fatigue is leaving me; I can feel it leaving me. And it can take a few weeks for that to happen, but even though they experienced fatigue from the drug, they're feeling great otherwise. So I do have patients who aren't noticeably feeling a lot better on the drug, but as long as they're not toxic, we're keeping them on it for those 10 to 12 weeks, and then we'll stop it and see what happens.

[00:36:32.04] Scott: You talked a little bit about the difference between Herxheimer reactions and this more neurological toxicity. Are there strategies other than regulating the dose that can help minimize that potential? Or is it really primarily about the dose?

[00:36:47.11] Dr. Dan K.: Yes. So all of the above, at this point, I am becoming progressively more proactive at recommending supplements that will help them deal with toxicity in general. So first of all, all of my patients we certainly do some sort of evaluation of their detox capacity, we're looking at methylation, for example, and we're giving them binders and so on.

In addition, because of the role of copper, I'm now giving them zinc; I'm recommending antioxidants, particularly alpha-lipoic acid. And I'm giving them a supplement that will help hepatic detoxification, so it has a number of agents in it like NAC and ALA and broccoli extract and silymarin. And becoming more and more proactive about adding those in early on to help detox and also to help protect the targets of this toxicity.

As you know, zinc will decrease copper and activation of copper, causing lipid peroxidation, what seems to cause the pathology of impacting the nerves because it will degradate the myelin sheaths. We're learning more all the time, right? And so like I said, I don't like to give people a whole lot of supplements and overwhelm them. And at the lower doses, I might not give them a lot, but as they're increasing the dose, I'll add those in before they become toxic so that hopefully it'll protect them.

[00:38:45.28] Scott: So it's an interesting question around supporting the liver because we know that in alcoholism, part of the reason Disulfiram is working is essentially by kind of stressing the liver's ability to process alcohol is my understanding. So it sounds like there are not concerns about supporting the liver in terms of Disulfiram potential ability to help with Borrelia and Babesia, correct?

[00:39:07.19] Dr. Dan K.: If I understood you correctly, not correct. The reason we prescribe Disulfiram for alcoholics is because it inhibits acetaldehyde dehydrogenase. We see elevated levels of acetaldehyde, and yes, that can cause toxicity, a lot of toxicity. But we're using it as a deterrent so that they'll have one drink and get a bad hangover and won't go on a binge. And again, I have no idea how successful that is among alcoholics since all we have to do is stop the drug. I don't see that population of patients, or I have one patient who is a former alcoholic, and he said yes, we used to laugh at that drug because we were so hungover all the time it didn't even matter if we took it, if we took Disulfiram.

So we do know that Disulfiram can cause hepatic toxicity probably because of its metabolites, not a direct action of the Disulfiram, and I do see elevated liver tests. Now in most people, it's a minor elevation, and we are following that closely, and we give the liver support as I've already described. But I do have one patient whose liver enzymes went up into the 300s despite all the liver support we were giving her, and I said I'm sorry we have to stop the drug even though she really didn't want to.

And that was not a very high dose, but she could not have been on more than a maximum 125 milligrams a day of a woman that I'm going to guess; she was a hundred and forty-plus pounds. So yes all I can say is some people are going to be more susceptible to that toxicity than others, but that's one out of a hundred, and I certainly have several patients who I see minor elevations of the enzymes, and they don't go up any further we just follow that along. We see that with drugs, we're using anyway, whether it was the anti-malarial drugs or whatever; we see minor elevations in liver enzymes.

[00:41:15.12] Scott: I read recently that kind of be ideal scenario for Disulfiram is for it to enter the circulatory system more directly, and to not be broken down into its metabolites. That if it goes through the stomach and the liver and so on that less actually enters circulation.

So I'm interested in your thoughts on that, and then kind of where does that lead us relative to the format of Disulfiram, meaning tablets, enteric coating, sublinguals; I'm seeing more liposomal. What are your thoughts on the different ways we potentially introduce Disulfiram into the body?

[00:41:49.20] Dr. Dan K.: So I would say we don't know the best way yet, there's more data we need to accumulate. In terms of liposomal, which, as you know, really helps facilitate the drug getting into cells more successfully, I think that's a bad idea. We know the Disulfiram is having an impact; our problem is it causes too much Herxheimer effect. I don't agree with making liposomal variations on Disulfiram; it just doesn't make sense to me. I'm not concerned about absorption in terms of antimicrobial function; it clearly is having antimicrobial function no matter how we give it, and like I said, that's obvious from the Herxheimer reactions. If anything, I'd like to slow it down. But the issue that you're bringing up is well, what about the metabolites and so on.

Dr. Rajadas says that it is broken down in the stomach, that is stomach acid will break it down into some of the toxic metabolites. And then he said take it on an empty stomach, and so I get back to him, and I say excuse me, if you take on it on an empty stomach, then it's going to be more exposed to the acid rather than on a full stomach when the acid is buffered by the food. He hasn't responded to that yet, but I think I'm going to guess he's saying well take it in enteric-coated on an empty stomach, and then it'll be more available in the intestines, I actually don't know.

I can tell you what I'm recommending, which is if you get enteric-coated capsules at the compounding pharmacy and so on. Then it's one dose, and but I want to slowly progress the dose unless I'm going to prescribe a handful of different doses for patients, then they're going to combine them to slowly progress the dose. I tell people just to take the tablets and to cut the tablets, but to take it with food.

And that clearly helps with nausea, and so on, I have no way of measuring the toxic metabolites when we do that. Like I said, they take it with food, they take the zinc with food and say vitamin C with food, and all of those can potentially cause an upset stomach, taking with food usually deals with that. And as I said previously in splitting the dose, and so that's how I'm recommending it at this point.

[00:44:19.23] Scott: Let's talk about some of the things people may need to avoid while they're on Disulfiram. So are there particular foods they need to avoid? Is it common that you see negative reactions when patients are exposed to alcohol? Either in let's say herbal tinctures or personal care products, how important is it to avoid those things to make the Disulfiram more tolerable?

[00:44:43.05] Dr. Dan K.: Okay, let's start with alcohol. Obviously, don't drink alcohol, but there's alcohol in extracts as you've mentioned, there's alcohol and in some foods that we want to avoid. In terms of the extracts, I do slowly taper them off the extracts, but in the meantime, I'm going to tell them to put it in just-boiled water, wait ten minutes, and most of it evaporates off. Now I've been asked for data to show to demonstrate that I don't have the data, but clinically it seems to work. In terms of personal care products like lotions, certainly aftershave, mouthwash, there's some products we know have a lot of alcohol in them. It surprised me that lotions and body odor products, antiperspirant really surprised me that these things have alcohol in them, I had no idea.

And then when I found out I said well how much alcohol can it have in it, and how much is going to be absorbed? Guess what, people react to it. I don't know that all people react to it, but I remember one person who said oh yes, I was doing really well I put this lotion on me and whoa had a bad day. So I'm recommending to people that they avoid anything with alcohol in it, and so far so good in that department. In terms of foods, one of the issues is yeast. Now yeast metabolically breaks down to acetaldehyde as well.

So if people have Candida issues, I'm going to treat that before I get them on Disulfiram, and they're going to be on a no sugar, low yeast probably low carb diet and get that under control before I initiate Disulfiram treatment. I'm going to say, but for all my patients, I'm going to tell them to have no sugar at all, which will not only stimulate yeast but also will suppress the immune system and so on. So I find that, and this happened to me personally, but as well as my patients on Disulfiram, I'm more sensitive to sugar. I'm actually not sensitive to sugar; I was just blessed by not even liking sugar, not liking sweets. But I noticed I had like a teaspoon of ice cream, and whoa, I can feel that in my head.

Almost as if I had a little wine when I mean a little wine really, I became very sensitive to sugar. And then we also recommend people avoid fermented foods in general and vinegar. I had a patient, who sprayed some vinegar on her refrigerator to clean it, and she smelled the vinegar and then whoa she had a reaction just from that. Other fermented foods can include some soy products and anything pickled, sauerkraut, olives, kombucha; I had a problem with kombucha.

I'm like, why do I feel lousy, and then a friend was over and said I don't know if I want to go on Disulfiram because I'll have to stop kombucha, and I said what? Then I found out okay, it's fermented, and it has alcohol in it. So yes, these are products that I absolutely recommend people don't consume while they're on Disulfiram.

[00:48:13.15] Scott: Let's talk about either supplements or pharmaceutical medications that might be contraindicated when someone's on Disulfiram. So from your comments already, we can kind of get the idea that supplemental copper probably is not ideal while we're on Disulfiram. But what about other supplements and maybe even some of the Azole medications in terms of their use with Disulfiram?

[00:48:37.09] Dr. Dan K.: Right. So Azole medications tinidazole, metronidazole, these are medications that are contraindicated, and that makes us suspect of any of the drugs in the Azole category, which haven't been studied yet in terms of their reactions when given simultaneously with Disulfiram. Some of the antidepressants, there's some literature on Sertraline, which is Zoloft, which makes us wonder about other SSRIs we don't know.

Tricyclic anti-depressants there have been some reports, and this would include amitriptyline and Trazadone, we don't use them as antidepressants anymore, but a lot of people are using them for sleep or neuropathy and so on. I know there are other medications, and I'm trying to remember what they are; I know when I looked it up, they're not medications that my patients are typically on. PPI's

there's some interaction, statin drugs there's some interaction, I try to get my patients off of both of those drugs regardless. So clearly, we have to be aware of drug interactions, as we are with any drug that we're prescribing.

[00:49:55.07] Scott: And can patients taking Disulfiram to tolerate it if they have sulfa or sulphur sensitivities, that's a common question that I've gotten?

[00:50:03.08] Dr. Dan K.: That was one of my first questions to Dr. Liegner, I said wait a minute this is sulfur drugs, he said no it's not, it's not a problem. It's actually not a problem even though Disulfiram sounds like a sulfur drug; it's really not a problem.

[00:50:17.05] Scott: In your patient population with those that have done Disulfiram and then stopped, what's the longest sustained remission that you've seen to date?

[00:50:25.20] Dr. Dan K.: I think it would be about three months, and I think one of the issues there is I progress people's doses so slowly that even though I've been prescribing it for over half a year, I don't have more than a dozen people who have totally finished the course of Disulfiram, I think it's only been a few months.

[00:50:52.27] Scott: And when people stop Disulfiram, have you in any case seen relapses? Do you find that some people need to continue it long term or even indefinitely in some scenarios?

[00:51:03.12] Dr. Dan K.: I definitely see Bartonella relapses, not necessarily Lyme or Babesia. But I am actually continuing its long term in people who we don't feel comfortable progressing the dose, usually because of Herxheimer and detox problems. So they're on a lower dose, much lower than our "target dose based on weight" and they're doing well. I have a patient who is very, very sensitive; I really can't explain it, but giving her different benign supplements that virtually everybody tolerates. She had problems with, she was clearly hypothyroid, and I really worked to find one of the thyroid drugs that she could actually take its low dose.

We were able to get her on Disulfiram, and I'm going to think that she was on Disulfiram about 31.25 either every 2 or 3 days. And she says wow I feel better; this is the best energy I've had in years and so on. And I said we're not going to increase the dose, we're just going to leave you there and have you check in every few weeks. Because I'm sure I could Herx her easily if I started progressing the dose using the regular protocol, and if I did Herx her, then she stopped tolerating virtually everything.

And so yes, in fact, I am thinking of just leaving some people on these somewhat lower doses and just leaving them on it, because they're doing really well, much better than they were doing when they are on the usual antimicrobial therapy. They're saying this is the best cognition I've had, in memory which is a funny expression. And it doesn't seem like they tolerate going to a higher dose, so we're leaving them on 125 a day or whatever and just checking in.

[00:53:12.04] Scott: And we've talked about this prior to our conversation today, but I want to bring in the whole topic of resistance. And so in the long-term use of Disulfiram, I know people will ask is there then the potential that Borrelia and Babesia become resistant to this compound?

[00:53:29.24] Dr. Dan K.: So is there a potential anything's possible, but thus far probably not. There are studies done on Borrelia that actually demonstrate this microbe does not develop resistance to antimicrobials over the long-term, and that's been my clinical experience. I presume that'll be even more so for Disulfiram because it's so good at apparently dealing with biofilms as well as hitting persister cells. So my guess is not, even though we don't have data on it.

[00:54:08.10] Scott: So I wanted to jump in shortly to the biofilm conversation, so let's do that. So one of the challenges with antimicrobials in the past is that they often don't penetrate these biofilms or protective layers that house all of these different microbes in a community. How does Disulfiram penetrate into these protected biofilms? And what's the role of carbon disulfide?

[00:54:29.01] Dr. Dan K.: Well, in a way, you're answering your own question. I mean, there is a suggestion that one of the metabolites, potentially toxic metabolites I hasten to add - carbon disulfide may facilitate entering the biofilm community. I found a paper in the dental literature that Disulfiram actually can help destroy biofilms.

As you know that dentists are very interested in biofilms actually before we were, right? Because plaques are in biofilm communities. So Disulfiram, along with other drugs, can actually destroy biofilms, and perhaps that's the carbon disulfide - I don't know. But again clinically, the fact that we're not seeing relapses when people stop to Disulfiram or generally not seeing relapses suggests that we are dealing with the biofilm community.

[00:55:36.21] Scott: Let's talk a little bit about pregnancy and children. So in someone that has Lyme disease and may be pregnant, is there any information on the use of Disulfiram during the pregnancy to potentially prevent transmission to the unborn child? And then how young in terms of using Disulfiram in children, how young can we potentially go?

[00:55:57.21] Dr. Dan K.: The limited data we have suggests we should not use it during pregnancy, and it's very limited data, and it's we're better safe than sorry. We don't get into any sort of cowboy-like attitude treating pregnant women for certain. Also, you know that Disulfiram, according to the FDA, is not approved for use in children, that doesn't mean it can't be used in children. Actually, it's not approved for the treatment of Lyme disease either, right? We use drugs off-label all the time. And I have been using it in adolescence as low as 12 years old. I'll point out that I have 12-year-old patients who are larger than I am, and the weight issues are not necessarily different than the adults that I'm treating.

We dose accordingly. Is there any reason we can't use it in younger children? Only the lack of experience. And then modifying the dose, I would certainly consider using it in a ten-year-old who weighs 80 to 100 pounds and giving them just ten milligrams. Certainly if a patient with Lyme and assorted co-infections has been treated for a couple of years with the standard antimicrobials, and it can't keep it under control, or they relapse continually when we try to take away any of those antimicrobials, I think that Disulfiram should be considered in a very cautious way, and always with the consent of the parent, I think it's important for doctors to protect themselves, document in the chart that the parents understand it's not approved either for this use or for the age group and have the parents sign off on that and then be super careful.

[00:57:53.21] Scott: Do you have any thoughts on why we historically have not seen a lot of the similar side-effects in the alcoholism population relative to those with Lyme disease. It sounds like a lot of the side effects we're seeing in Lyme are not traditionally seen with Disulfiram outside of the Lyme population.

[00:58:12.24] Dr. Dan K.: It's true, and my patients have asked about this. For one thing, I think alcoholics are healthier than we are. I mean clearly, unless they have end-stage cirrhosis in which case they're really unhealthy and their high ammonia levels and their encephalopathic and then they don't know that they're just confused all the time and they wouldn't even be able to report side effects. But the fact that they can down a bottle of wine or two, that they can drink several six-packs or whatever types of hard liquor

they can drink. I don't have any Lyme patients that can do it, almost all my Lyme patients will say oh yes I don't tolerate alcohol, I can have a little bit, and then I don't feel well, and I'm hungover the next day. I don't think our patients can become alcoholics, I think alcoholics can develop Lyme, but then they probably aren't going to tolerate alcohol anymore.

So their detox systems seem to be in much better shape than we as chronic Lyme patients. And I'll just mention in terms of that detox because it didn't come up earlier. We really investigate methylation a lot in these patients and make sure we try to improve their methylation pathways with whatever supplements we can, so that their detox systems are working more efficiently. Are there other issues with alcoholics? I wonder whether, how much they report symptoms of toxicity given if they're truly an alcoholic, hung over a lot, and they distinguish an encephalopathic symptom from just a straight out hangover? I don't know, I just don't know.

But it is clear; it is clear that we're seeing more toxicity in our chronic Lyme patients. I think that it is related a lot to our impaired detox pathways, it may also be related to the significant neuroinflammation, systemic inflammation for that matter that most of us had if we have an active microbial population. And I also want to point out that my patients who are on Facebook describe an overwhelming number of people with neuropathy in particular and some encephalopathic symptoms like the brain fog and depression. I'm starting to see that, but not nearly as much as the reports on Facebook that are then shared with me.

I do think that people getting into trouble often are taking too high a dose that they've progressed the dose too rapidly, or also, I understand that some doctors are not taking them off their other antimicrobials. In fact, that happened to that one patient in Ireland that I described to you, this is a person who is on triple antimicrobial therapy and 500 milligrams a day of Disulfiram. So as I said, I'm taking people off those antimicrobials, slowly; I have described it as a dance, so as we slowly progressed the dose of Disulfiram, we're slowly decreasing the dose as the antimicrobials.

[01:01:51.25] Scott: Yes. And I think another challenge, unfortunately, a lot of people are also or some people are also getting access to this medication that don't really have a doctor closely monitoring them, don't understand how to use it and I think it's very important with these types of potential side effects that people are working closely with their doctors when they're using Disulfiram.

I want to talk a little bit more about the copper issue, so you mentioned copper that elevated copper potentially is associated or correlated with the neuropathy that can persist over time. So is something like a copper IUD a potential contraindication? Do you do testing for copper levels in the body before you actually have patients using Disulfiram?

[01:02:34.22] Dr. Dan K.: Wow, I never thought about the copper IUD; this is the first time it's come into my consciousness. I'm trying to think if I have any patients on a copper IUD at present. I've had patients who don't tolerate the copper IUD and have had to have them taken out not long after they were inserted.

So no data and no clinical experience with that. I do not measure copper levels before I start treating patients, but I will start giving people zinc, which, as you know, will decrease overall copper load as well as other supplements to try to decrease the toxicity. And as we mentioned before, copper seems to be playing a role in the peroxidation of the myelin sheaths of nerves leading to the neuropathy.

[01:03:29.15] Scott: And do we know in those that have this persistent neuropathy that does not seem to resolve after they stop treatment with Disulfiram, do we know does it tend to resolve over time, or is it then something that requires a different treatment focus? What happens in these cases of persistent neuropathy?

[01:03:48.06] Dr. Dan K.: So I'm happy to report I don't have to deal with that in my patient population. I certainly have had some people with some neuropathic symptoms that not severe or significant, and what I'm hearing from others is that it does tend to attenuate over time. Alpha-lipoic acid is an excellent supplement in terms of helping to resolve that issue, particularly when given intravenously. But what I'm hearing from people who are not my patients is that the neuropathy does get better over time.

[01:04:31.19] Scott: Okay, very good. Let's talk a little bit about side effects like anxiety and paranoia; my understanding is there's some interaction between Disulfiram and the inhibition of dopamine beta-hydroxylase. What are some of the observations you've had relative to some of these mental, emotional type, or mental health side effects with Disulfiram?

[01:04:53.18] Dr. Dan K.: Right, so dopamine beta-hydroxylase is an enzyme which converts dopamine to norepinephrine. So it's very important in terms of our neurotransmitter balance, and if we inhibit dopamine beta-hydroxylase, then we're going to see low levels of norepinephrine and high levels of dopamine. And this can result in some severe mood changes and even manic or hypomanic symptoms and behavior. This is probably mediated by the copper disulfide metabolites of Disulfiram. So as you mentioned, there are reports of psychosis with Disulfiram.

There are not very many cases; I mean, this is scant in the literature. And in the case reports that I've read, the psychosis goes away after a month or more off the Disulfiram. And I suspect it is related; it is related to the high dopamine levels. I have not seen any psychosis with my patients, thank God; I certainly have seen mood issues, though. You mentioned depression, I've also seen anxiety and irritability, and again we have to distinguish that from a Herx reaction because, of course, these microbes cause a lot of neuropsychiatric symptoms, and they can manifest these mood symptoms as part of a Herxheimer reaction.

But if we do distinguish those symptoms from a Herx and say oh no, this is probably neurotoxicity; again, I'll immediately stop the drug. And if we catch it early, and I'm always advising my patients to let me know right away if they have these symptoms, they stop the drug, and within 24 hours, they say oh no, I feel great.

And again, that's not a Herx reaction; as you know, it can take days for a Herx reaction to go away. And as I said previously, having experienced brain toxicity from this drug, I've gotten very good at recognizing it in my patients. And I'm always going to be more safe than sorry; I'm always going to stop the drug or pull back on the dose if I'm remotely suspicious of a neuropathic or encephalopathic symptom.

[01:07:28.29] Scott: This is an interesting question. A listener asked about body odor while using Disulfiram, and how it can be managed for those people in a work environment. Is there some body odor associated with the use of Disulfiram?

[01:07:41.22] Dr. Dan K.: There is, there are a host of what we call minor side effects. We're calling them minor because they're not resulting in some organ damage, but body odor is one of them, bad breath is another. Constipation, bloating is another.

So there are a handful of these so-called minor side effects, I don't know what the pathophysiology is; although it would be interesting to learn. I don't know what to do about that, I don't want people to put on perfume for certain because at least we try to have a scent-free office, and I do my best to coach patients. You know really don't wear chemicals, don't wear scents even if you don't react to it, trust me people you come in contact with do react to it.

[01:08:26.20] Scott: And most of them probably have alcohol in them as well, right?

[01:08:30.21] Dr. Dan K.: Right. So I don't know what to do about the body odor quite frankly.

[01:08:36.09] Scott: Okay. Are there any specific genetic mutations or predispositions that you've observed that make it more difficult to tolerate Disulfiram?

[01:08:45.15] Dr. Dan K.: Well again, I certainly will do my best to optimize the methylation pathways. There's no question in my mind that impaired methylation is going to make it harder to tolerate this medication, and as you know, it's harder to tolerate almost any other thing to treat microbes.

Other than those mutations I'm not aware, I mean, I don't doubt that there will be. You're probably aware of this when a lot of psychiatrists will order a genomic test that will determine on the basis of DNA studies which drugs are better and which are worse. And maybe at some point, we will have the data for Disulfiram as well.

[01:09:39.28] Scott: One of the challenges with traditional antibiotics is their negative impact on our microbiome. Do we know if Disulfiram has any impact on our healthy biome if it's killing microorganisms, does it also impact our good guys as well?

[01:09:55.21] Dr. Dan K.: So shortly after I talked with Dr. Liegner, I called up Dr. Lewis, Kim Lewis; I'll just remind the listeners that he's the microbiologist at Northeastern who gave the lecture at the conference in 2016. Where he described the impact of Disulfiram on Borrelia burgdorferi in the laboratory where basically sterilized the culture, and there are no persister drugs, so I called him up just to let him know some of the clinical experience we were having, which to a large degree were also based on his laboratory experience.

And so we had a nice discussion, and he said well I chose Disulfiram because it won't affect the gut microbiome and I said well why won't it? He said, well, it's not an antibiotic. Well, if we define antibiotic as an FDA-labeled antibiotic, it's not an antibiotic; it's clearly an antimicrobial. And I said well wait a minute it's killing bacteria, we know it kills Borrelia burgdorferi, and we know it kills Babesia. And it's been shown to hit gram-positives like staph and strep. He said yes, but with those other bacteria outside of Lyme, they have very high MICs, meaning it's not very potent against those bacteria.

He said I don't think it's hitting the microbiome without any data, looking at the microbiome of patients who've been on Disulfiram. I mean he's just working in the laboratory, he's not doing clinical studies on patients. I question his conclusions. It is hitting bacteria; there are studies where it's a decent drug against some staph and strep species. I presume it's going to hit the microbiome as well; I still keep people on probiotics, people with yeast problems, I'm keeping them on Nystatin or other agents that are going to keep yeast overgrowth down. And you know at some point maybe we'll have more specific data on it, but and when I extrapolate what we know about the Disulfiram, I suspect it's hitting the microbiome.

[01:12:19.08] Scott: Where do you think the conversation with Disulfiram will be a year from now? And if we have Disulfiram as a continued tool in the toolbox, where do you see additional tools needed in order to help people with chronic Lyme fully recover their health and their lives?

[01:12:36.05] Dr. Dan K.: Wow, well, if you ask me a year ago, I'd have no idea where we'd be now. So it's hard to look into the future. I think that we will be impressed with how effective Disulfiram is in treating Lyme and Babesia, and we will become increasingly aware of the potential toxicity; this is a powerful drug; that's good and bad. It's clearly the best drug I've ever used against Lyme and Babesia, and there's no question. And it has potential toxicity, which I think can be mitigated a lot by careful dosing and supplementation, as well as really frequent interactions with the patient.

Like I said they're checking in with me every two weeks which means I'm getting a lot of emails, but it's good I mean we're careful, we're going slow. In a year from now, we might find out that Disulfiram is hitting other microbes that we don't know about. We're already aware that it's hitting, well these are like very small reports in the literature; it's hitting Aspergillus - a fungus.

Probably hitting other fungi as well, and scabies so it's probably hitting maybe helminths; and it makes it interesting like it's hitting scabies, I bet it would be good for Morgellons not just because it hits Lyme, not just because it hits Lyme but because it's a vermicidal haven't thought about that. I don't have any Morgellons patients at present. What else? In a year from now.

[01:14:32.18]Scott: And it's interesting. One of my takeaways from this conversation was the Aspergillus piece, and so we know that many people with chronic Lyme disease also have concurrent mold illness from water-damaged buildings.

There is some debate that many people think that we can become colonized with Aspergillus and other fungi that create mycotoxins in the body that continue this inflammatory process. And so it makes me wonder if Disulfiram may even potentially have a role in those that have had exposure to water-damaged buildings.

[01:15:04.04] Dr. Dan K.: It's a great point. I'm glad you brought it up. As you're aware, there are many doctors out there who are good Lyme doctors, and they espouse the idea that oh, you can't even begin to treat the Lyme until you deal with the mold and the mycotoxins. I've never really subscribed to that because often while we're treating the mold and mycotoxins, we can start some antimicrobial therapy, and people feel better even if it's not going to be as effective until we clear up the mold and mycotoxins. Because Disulfiram has been so effective, I'm starting it earlier in that process than I used to.

But I still, now let me back up, you mentioned that a lot of our patients, I would say almost half of my patients have mold and mycotoxin issues. And it's not that a whole lot of other people don't have mycotoxins in their circulation and aren't exposed to mold, but they're not getting sick from it like our Lyme patients are. Still not a good idea, right? But in a household of people that are in a moldy environment, it's the person with Lyme who's getting sick from it. Most of the others don't, and that's not a hundred percent.

Clearly, they're a lot of people out there who don't have Lyme. So what I do with my patients is I do my best to help them mitigate whatever environment they're in, if they're still in a moldy environment. And I'll put them on binders, which is a good idea anyway to decrease circulating neurotoxins. I don't put them on a systemic antifungal, which I might have otherwise, for the reason that you said - I'm suspecting that the Disulfiram is a systemic antifungal.

You mentioned something sort of eluding to a controversy around whether or not these mold toxins are problematic because our bodies don't know how to get rid of them or because we continue to produce mycotoxins because we have an endogenous load, that is we have fungal colonization, and I could say a hundred percent is the latter. And I'm a great example of that because I'm Medicare age and I decided oh what the heck I'm going to get a mold toxin test because I can get it for free at RealTime Labs. Oh my God, I mean, I was like one the highest I've ever seen.

So I started on; I said, well, I'll start on some binders and saunas. And after four months, I tested again no change. Then I added Itraconazole, and for people don't know it's a systemic antifungal drug. Oh, I was also on a nasal antifungal in the first three months or four-month trial, and that's to kill fungi that are colonizing the sinuses. Okay, no change after four months I added Itraconazole, another four months, it was down 50%, another four months, it was down another 50%.

There's no question in my mind that that fungal colonization is a big issue with many people with mold toxins. And of course, they have to get out of a mold endemic area. And while we're talking about that, there is a lot of doctors that are getting HLA testing to see if they have specific DNA sequences that suggest their bodies don't know how to get rid of those toxins. I was doing that initially; I don't think I ever saw a patient who didn't have some of those mutations. I found it totally unhelpful.

I'm going to treat them the same anyway; I don't think the issue is they can't get rid of the mold toxins because guess what? We're doing a urine test; they're excreting mold toxins. And it's not just what they're eating, it's clear that the levels we're seeing is not just what's in the food, so I don't bother with that testing anymore.

[01:19:40.28] Scott: Yes, absolutely. Lots of good points there, I resonate with a lot of what you said. So we have some exciting information for people, you have a book that's coming up. So tell us a little about the book, when will it be out, where can people get it, and learn more about it?

[01:19:55.10] Dr. Dan K.: Okay. Past four years, I've been writing a book; I enjoy writing; this is not something difficult to do. My mother has written over a dozen books, my mother blessed memory - she's not with us. But I enjoy writing, and I'm 70 years old at this point, even though I don't intend to retire, I would like to be passing on all the information I have. As you mentioned, I've been practicing for 40 years; I have extensive experience, not just treating Lyme patients. But by treating all the comorbidities that we see in that population of chronic tick-borne illness.

So my initial idea was I really want to write a book for physicians because I trained physicians, and I really want to pass on this information. So also obvious that most of the people who will be buying this book will be patients, not physicians.

So I wrote what is can easily be used by physicians as a text book. It describes how to evaluate patients, what kind of laboratory tests to order, and how to treat them, but I do it in lay language. And I think patients will find this very, very useful in terms of identifying with what I'm describing, there are a lot of case histories in there, and I'm sure patients are going to relate to these case histories.

I want to back up one second; it just occurred to me when you said what will happen in a year from now? One of the things that may happen is we will be treating acute Lyme disease with Disulfiram. Which was Dr. Rajadas' first idea; at least there is a press release that came out of Stanford with that study that was published in 2016. In which that's what he described, he didn't describe the treatment of chronic Lyme; he described treatment of acute Lyme in that press release.

He may have done that for political reasons because researchers at academic institutions don't want to use the word chronic Lyme, I don't know. But I think it would be a great drug for acute Lyme disease once we have the courage to do that, rather than use the standard antimicrobials.

[01:22:22.19] Scott: Well, and it's never made tremendous sense that we focus on doxycycline with the acute Lyme because we know that's not going to do a lot for co-infections that are almost universally present anyway, right?

[01:22:32.10] Dr. Dan K.: So yes, I'm glad you brought that up. Doxy is not a particularly good drug for Lyme and a lot of other things. I mean, the good news is it is the drug of choice for a couple, so we'll say for Ehrlichia, Anaplasma; for Rickettsia. On paper, it treats Mycoplasma and Bartonella and even has some activity guess Babesia, but it is a lousy drug for all three.

So I think the reason it's had popularity is because it hits those other co-infections which are not nearly as common as the Babesia and Bartonella and Mycoplasma species. No, I don't use Doxy very much, and also, I'm in the southwest. It's a fairly sun-drenched area, and doxycycline causes so much photosensitivity that it's simply not well tolerated around here unless you want to stay inside. Yes, so I don't recommend doxycycline. And then that gets to well how do you treat acute Lyme? And that's a whole other story, right?

[01:23:38.12] Scott: Another show. So let's come back to your book. I'm excited for people to learn more about that.

[01:23:43.03] Dr. Dan K.: Yes. So I'm very excited about the book, the title of the book at present, my title of the book is Recovery from Lyme, the subtitle is The Integrated Medicine Guide to Diagnosing and Treating Tick-Borne Illness. I hope it comes out this year; I really don't know. Right now, my agent is taking it around to publishers, and we'll see what happens. And I think the feedback I've received from practitioners as well as lay people who have looked at it said this is great. Many practitioners have said whoa, I wish I had had this when I started treating Lyme; it's just so much information. For example, I would say about half my patients with acute Lyme disease have co-infections. I only see about a dozen patients for the acute Lyme disease a year, right? 99% of my patients have chronic infections.

Well, we have to know how do we sort that out early on. Another, here this is very interesting. I would say about a third of my patients with acute Lyme disease have chronic Lyme but didn't know it. And I said ten years ago when you suddenly develop an anxiety disorder and sleep problems etc. you get it back then, and guess what you got it again. There's just an awful lot of stuff based on a lot of clinical experience, but also a lot of training internal medicine, environmental medicine, nutrition, and so on. So I think I bring a lot, a lot of experience into that literature.

[01:25:30.05] Scott: Beautiful, yes I'm excited to explore the book in more detail. The last question that I have is the same for every guest, and that is what are some of the key things that you do on a daily basis in support in your own health?

[01:25:40.27] Dr. Dan K.: Well, good question. One is I do my best to get a good night's sleep; I go to the gym a few times a week. At this point, it's really to maintain not to build up muscle, and fresh air and sun. Emotional well-being is so important to be able to identify when I'm feeling stressed and to deal with that as usually just letting it go. And those are really important; of course, I keep up on my supplements. I'd say for me. Personally, I am blessed by having three daughters and six grandchildren, and I connect with them as much as possible, and it's such a blessing in my life.

But I'll also say that I'm really passionate about what I do. It's interesting that so many doctors, instead of retiring they semi-retire, because it's a very rewarding profession, or at least it has been up until recently with the electronic medical records which are inducing a strong dropout rate among both doctors and nurses. Yes, I mean, what a wonderful thing to be sitting with people and having the opportunity to help them have a better life.

And then watching that happen and feeling their gratitude, and I'm going to get a little choked up talking about it because it's just hard to imagine a more rewarding experience than to be in a position where we can so quantitatively and qualitatively help people enjoy life who couldn't. And in that context, when I first see people, and they may not know this, I really spent about three hours doing a complete history, physical exam going through notebooks of past laboratory data and medical records. And then say okay, yes, pretty sure you not only have Lyme but you have these co-infections, and I'm pretty sure you have these detox issues. And by the way, you really need to check for mold, and I think your adrenals are tired, and we need to check this and that endocrine issues, and it's really overwhelming for patients.

But I tell them look, I know this is overwhelming, we're just going to take it one step at a time, but it's not overwhelming for me. I got it; I have it handled on this big picture. And I tell patients I'm trying to think when I don't tell patients this, but it's been rare. I tell patients because I really believe you're going to get better. It might be slow, it might be two steps forward and one step backward, but I believe you're going to get better.

And sometimes they're so depressed and hopeless that they don't believe it, and I say you don't have to believe it, you just have to take these steps, I believe it and this is my experience. Maybe less than once a year, I see a patient oh boy they are so inflamed, and they've been down for so long that I really question whether or not they're going to get better, that's rare, that's really the exception. But just giving them hope wow, what a blessing that is. And then, as you know they've seen dozens of doctors who have written them off, and they feel both hopeless and helpless.

And the other thing I tell them is that I have their back, that if they have problems they email me, I should be able to get back to them within 24 hours even if I'm on vacation. And that's really important, so many things can go south instead of north, they email me I took this medication, and this happened what do I do? Great, thanks for contacting me. Here's what we should do.

Along those lines I always stagger interventions, never start two things at once, always spread them out so we know you're tolerating even benign supplements, because there would always be someone who reacts to something you never know, right? And just the fact that I'm there, I'm real, I'm hopeful, and they trust me, which is a gift to me. And I believe they're going to get better because I embody that belief, they start to believe it as well.

[01:30:30.11] Scott: Well I think it's clear you're living your purpose and your passion, you certainly have made a difference, you certainly are making a difference and will continue to make a difference. This has been such a fun conversation; I learned some new things. I know people listening that are going to learn some new things. And so I just want to thank you for being so generous with your time and all of your knowledge and everything that you've shared today, it's been a super fun conversation.

[01:30:53.15] Scott: Thank you, Scott. And thank you for what you do, I mean I'm really impressed. I'm really impressed when you sent me the list of questions, like wow, this guy has really done his homework, and I'm sure you do that with everyone you interview and every topic you discussed, so thanks so much.

[01:31:09.14] Scott: Thank you so much.

[01:31:10.17] *Thanks for your interest in today's show. If you'd like to follow me on Facebook or Twitter, you can find me there as better health guy. To support the show, please visit Betterhealthguy.com/donate. If you'd like to be added to my newsletter, visit Betterhealthguy.com/newsletters, and this and other shows can be found on YouTube, iTunes, Google Play, Stitcher, and Spotify.*