Lyme, Mold, and CIRS Explained: How Hidden Illness Hijacks the Immune System

Interview with Dr. Christian Navarro-Torres

SPEAKERS

Dr. Christian Navarro-Torres, Kendra Seymour

CNT

Dr. Christian Navarro-Torres
00:00
So when, when the patient tests positive for the symptoms and fails the VCS test, Dr.Shoemaker has estimated that there's a 90%, at least a 90% probability that you are likely suffering from CIRS by just looking at those two screening tools.

KS

Kendra Seymour
00:24
Hello and welcome back to Your Indoor Air Podcast brought to you by Change the Air Foundation. My name is Kendra Seymour, and today's episode is for anyone who's ever felt sick but couldn't quite get an explanation as to why. Maybe you've been told, hey, your labs are normal, or you're shuffled from doctor to doctor without answers. Maybe chronic inflammatory response syndrome or CIRs is at play. Now it's a condition that affects an estimated one in four people and is often triggered by mold and bacteria or other toxins that we're going to talk about today. But really, you know, as a foundation, we talk a lot about mold, it really is more than just mold, and that's why I'm so excited for our guest today. He's going to unpack some of that for us. But in this episode, we're going to explore the connection between biotoxins and the immune system and chronic infections like Lyme and Babesia, Bartonella, and why healing can honestly feel so complex and frustrating and even isolating at times. I have been there. So our guest today is Dr. Christian Navarro-Torres. He is someone who understands us both as a scientist and a patient. And you're going to hear about, you know, some of the diagnostic roadblocks, some cutting edge research, real stories of healing and what it takes to actually get better. Now, whether you're just starting your journey or supporting someone who is this conversation, I promise you, is going to be full of science. It's going to also be full of practical guidance, and, of course, hope so. Thank you, Christian, so much for being here.

CNT

Dr. Christian Navarro-Torres
01:50
Thank you so much. Kendra, this is really a pleasure and an honor, and I really admire and appreciate what Change the Air Foundation is doing for the community of people who are suffering from these chronic illnesses. Mold, toxicity, chronic inflammatory response syndrome, and I feel like you're at the forefront of something very important. So thank you.

KS
Kendra Seymour
02:14
Well, thank you for that, and you are too. So I'm going to give people a little bit of background, because I love talking to you, and we were joking before we got on that we could have like, five interviews with all the stuff that you're up to, but I want to give people just a little bit of background about who you are and what you do. So Dr Navarro-Torres is a cognitive scientist with formal training in cognitive psychology and neuroscience. He's the co founder of CIRS lab, where he hosts memberships for both patients and medical practitioners who are pursuing a high level of understanding around CIRS. He's also the Scientific Director of the CIRS Research Foundation, and works as a research consultant in collaboration with several CIRS practitioners. He is a CIRS patient still in recovery, and heavily relies on his experience as a hypersensitive patient to educate other patients and practitioners on how to work with complex cases like himself. And do not worry, we are going to link to all of your resources so people can easily find the CIRS lab and CIRS Research Foundation. But before we jump into our questions, I do need to take a moment to say a huge, huge thank you to two of our corporate sponsors, HNST Mold Inspections and The Green Design Center. We are a nonprofit. We are small. We rely on the generosity of our listeners, of our donors, and of companies like these two who make our work possible, our free resources, our policy work, the small scale research we fund, so huge thank you to those two sponsors. If you want to learn more about our corporate partners, or if you would like to become a corporate partner yourself, please head on over to ChangetheAirFoundation.org, and check out our about tab. You'll see all the information there. So let's jump in, though, because we have a lot to cover, and I wonder if we could kind of set the stage for everyone listening, because it's estimated that roughly 25% of the population, which is just over 50 million people, are susceptible to inflammatory responses to like mold, bacteria or other bio toxins. So can you give us kind of a high level, if that's possible, overview of what is chronic inflammatory response syndrome, and what are the symptoms, what causes it?

CNT
Dr. Christian Navarro-Torres
04:30
Yep, so I think it's always important to start in a high level picture of these things. I think it's in a way, to get people from all different levels on board. So when we talk about CIRS or chronic inflammatory response syndrome, the there's a word there in inflammatory, inflammation. I want to start with a basic

distinction of the immune system, because the immune system has sort of two sides of the same coin. And in that vein, inflammation has two sides and so they're each of them tied to these different parts of the immune system. So on the one hand, we have what we call the innate immune system, sort of your first line of defense. Whenever you encounter a foreign invader, it could be an infection, a bacterial infection, a viral infection. Those first days, when you get sick, right? You get all these flu like symptoms. You may get some fever, you may get some sort of pain throughout the body, sore throat, you know, a lot of sinus congestion. All of these symptoms are part of what we call the innate immune system. It's a non specific, coordinated response, initial response, to that foreign invader entering into your mucosal linings. And so the immune system launches this sort of non specific attack, which uses inflammation to right. In fever is an inflammatory response from the innate immune systemm right? The limitation of this part of the immune system is that it's not very smart or wise. It's just throwing an inflammatory attack at whatever is there. It doesn't necessarily know what is it that's entering the body, and in that sense, it can cause collateral damage, right? So a fever, if it's high enough or long enough, it can potentially be fatal for a person, right? So what should happen eventually is that this other part of the immune system, called the adaptive immune system, which is the wiser, more sophisticated part of the immune system, should start kicking in, and it's going to be sending all these immune cells that are sort of investigators or detectives. They'll start sort of briefing or trying to investigate the crime scene. What is it that's here? Exactly, who is the villain or the suspect? Let's profile it, and let's create a report, and then let's generate what we call an antibody, right? In order to have long term memory in response to that the antigens or the the toxins or the presence of the bacteria or the infection in a long term fashion, so that next time you encounter it, the immune system knows what to do. It doesn't necessarily engage the innate immune response, right? And this is how actually vaccines are supposed to work. It is supposed to trigger an adaptive immune response that creates an antibody, a memory trace, so that it knows what it's dealing with. So this is how an organized, healthy immune response is supposed to take place, some initial innate immune activity, so cytokines or inflammation from that side, that then triggers sort of the adaptive immune system to come in to selectively target the infection or the foreign invader, and then eventually create a memory trace. So what is CIRS in that context? So what we see in CIRS is dysregulation in the communication between these two sides of the immune system. So what we see is persistent activation of the innate immune system in the absence of the adaptive immune system kicking in to generate an antibody or memory trace. What is it that's triggering this dysregulation? It's biotoxins. So these are organic toxins produced by certain microbial organisms that could be found in different environments. The most common environment is going to be water damaged buildings, right? Where we'll have elevated levels of certain fungi and bacteria as well that can trigger this innate immune response and then set the innate immune system to stay in this indefinite, chronically activated state, and that behavior never shifts into, like I said, the adaptive immune system. So there's no antibody processing necessarily happening in response to those biotoxins. And so that sort of pushes the innate immune system to stay active or hyperactive in an indefinite fashion. And so over time, and you mentioned there there's a susceptibility aspect. So through research primarily led by Dr Richie Shoemaker, who really was the person who discovered CIRS back in the mid to late 1990s. He found that there's certain people who would develop chronic symptoms in response to this immune

dysregulation, and that there was a genetic basis tied to what we call human leukocyte antigen system. It's simply a set of genes that are involved in how your immune response, or your immune system, coordinates a response to antigens, including biotoxins and other things. And so certain people that carry certain HLA genes seem to have problem in organizing this immune response right. And so when they are living in these moldy places or water damaged places, over time, they can start triggering this chronic activation of the innate immune system, and now you have a very disorganized or dysregulated immune response, and that seems to correspond to roughly 20 to 25% of the population in the US, at least, that carry some of these gene variants that seem to make them susceptible to triggering this CIRS. In terms of symptoms, there is a long variety, or long list of symptoms here, right? And this is one of the tricky things about CIRS, that it's a multi system, multi symptom illness, where in traditional sort of through a traditional medical lens, it's really hard to diagnose because it sort of manifests in all of these different domains. Through research by Dr Shoemaker and colleagues, they've identified 37 symptoms that are the most frequently encountered in CIRS patients, and they can range from chronic fatigue to neurological symptoms that can include memory impairment, learning difficulties, mood swings, focus or attention problems, all the way to endocrine or hormonal problems throughout the body, which could include urination frequency or excessive thirst, regardless of how much water you drink. There's going to be, you know, gastrointestinal issues also in there, there could be also sleep problems or circadian related, circadian rhythm related symptoms. So there's a total of 37 symptoms that have been used for sort of formal as part of the formal clinical assessment and CIRS patients. So I'll leave it there for now.

KS
Kendra Seymour
12:24
Yeah,

CNT
Dr. Christian Navarro-Torres
12:24
You can take it from there.

KS
Kendra Seymour
12:25
No, that was super helpful. So there's I was jotting little notes of things I wanted to pull out because there were so many gold nuggets. I'm glad you you mentioned some of the symptoms, because I think people assume exposure is, maybe it's just allergy like symptoms, but it really is, you know, a lot more complex. We'll talk about some of the challenges with how you tease out CIRS from other conditions, because there is overlap. And I think that the alarm, one of the alarms we're sounding here, too, and we can unpack this little bit more later, is the neurodegenerative side of things, and how what that means, and we think about Alzheimer's and Parkinson's and all of these things that most people have heard of, and to know that

maybe there is a way to prevent some of this and reverse it. And it's interesting too that you mentioned the urinary symptoms, the frequency, because that was finally the oddball, I'll call it an oddball symptom, that really finally made our doctor sit up and say, hey, something else is going on. Because they were able to excuse everything, oh, you know, you're tired, oh, some people would just like that. But that was weird when it was 20 or 30 times a day and it wasn't tied to diabetes, and it wasn't tied to urinary tract infections, and, you know, they were ruling out all sorts of things. So that's really interesting. So, and the reason why I asked you to talk about the immune and adaptive response first is because I think sometimes people, when they come to this, it's a little overwhelming to understand. What am I reacting to, right? Because if I move out of that moldy home, some people will get better, but some won't, and they're like, well, I'm not being exposed anymore. So, you know, barring like some type of colonization, which I know can be a little controversial, we don't need to pack unpack that. But the the inflammatory response syndrome, it is what is happening to your body. It's why some of those people still continue to be sick. I once heard it explained, and please feel free to disagree. If this is not a helpful way for the lay person to describe it, that the innate immune system was kind of like the alarm system, sounding the alarm that something is wrong, and then the adaptive immune system comes in, and they're the kind of like the cleanup crew, and they're going to handle everything, and the disconnect happens when the alarm is going off, but that cleanup crew never shows up. Okay, okay

CNT

Dr. Christian Navarro-Torres

12:25

There's communication breakdown. That's a beautiful way. I wish I would have said that. Actually, from the get go.

KS

Kendra Seymour

12:57

I stole it from someone, and so it was what made it kind of click for me, in context of everything you said. So I wanted to put that out there for people. Yes, so, and I think something too we talked about a genetic component. And. I think I heard Shoemaker, please correct me if I'm wrong, he said, I think it was the one of the interviews I heard him about 95% of CIRS patients have the genetic disposition, but you don't necessarily have to have a genetic predisposition to develop CIRS. Is that correct?

CNT

Dr. Christian Navarro-Torres

13:35

Yes, there are cases, or documented cases where they don't carry any of these HLA genes that we typically associate with CIRS. So in that sense, this is really a very probabilistic right? Genes are always very probabilistic. It's never a yes or no or almost never, unless you have something like, you know, chromosome mutation, or like Down Syndrome or something like that, which is right? But for the most part, genes don't

operate necessarily in that way. It's more of an increased susceptibility, right? If you carry certain genes, like APOE4, certain variants, you might be more likely to develop dementia later in life. It doesn't mean that you're going to develop it. And it's the same thing for these genes that have been associated to CIRS. And in that sense, you should expect to have perhaps a small percentage of people who don't carry these genes and could develop that. And one reason that might be true is because what we see in CIRS is a it's sort of a short term adaptive response from the body to try to deal with the presence of these toxins. And this might be a very ancient behavior from bodies that can go, that can be traced all the way back into cells when they were developing. So in that sense, the point that I want to make is that we're all, in theory or potentially wired to have this kind of dysregulated immune response, but in its own dysregulation. It there is a lot of systematicity and the kinds of abnormalities that you see, which tells you that the body is trying to do something coordinated, but it's just not long term feasible for us.

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Kendra Seymour

17:12

Yeah, no, and that's helpful. And I mean, the whole genetics and epigenetic is such a fascinating field and all that, and we're learning so much every day, and all the work that Shoemaker is doing in this specific and colleagues and you in this specific arena is super fascinating. So let's talk about that. How are people diagnosed with CIRS? Because here's something I see it actually, it's a very specific criteria. And sometimes I see people say, hey, I have CIRS and they haven't actually been diagnosed following the criteria. Doesn't mean they're not sick from mold or water damage building. But can you talk to us about how it's, you know, diagnosed? And what kind of makes the diagnosis challenging?

CNT

Dr. Christian Navarro-Torres

17:53

Well, the I think the the challenging part of this is that there isn't a single test that will tell you, oh, yeah, you have CIRS. In the same vein, when it comes to the treatment, there isn't a single, you know, pharmaceutical agent or drug that will just fix the whole thing. And in fact, I think as we're advancing and science and medicine right in the mainstream world, we're learning that that approach is probably not feasible for a lot of illnesses, certainly not chronic illnesses in general. So I think that's the primary issue is, well, you're dealing with them again, multi system, multi symptom, illness that you can't just pinpoint at this one thing to sort of pin down. In terms of diagnosis, there's a couple of basic elements that practitioners who are trained in treating CIRS will usually follow. So, on the first and they're going to use screening tools. And there's two aspects or elements of the screening tool. The first thing is a visual contrast sensitivity test. It turns out that CIRS patients, when they activate the illness, they'll do this test that measures your ability to detect contrasts or shades of, let's say, black and white and gray of lines. And there's a very specific criteria or pattern of abnormalities in being able to detect these contrasts that we see in CIRS patients. So practitioners will often start with a VCS or visual contrast sensitivity test to see if

they fail or pass the test. This is actually readily available online. If you go to survivingmold.com you can purchase a test for like $15 and it takes like maybe five to seven minutes to do the test on each eye. And then you'll get a pass fail based on the criteria that's been established for CIRS. So then on, combined with that, we have a symptom cluster assessment that we briefly alluded to. There's a total of 37 symptoms in this sort of questionnaire that have been used in CIRS, and typically, you'll see a certain number of symptoms that will show up, not necessarily specific symptoms, in the 37 symptoms, just as a certain number across different clusters of symptoms that group together. So when, when the patient tests positive for the symptoms and fails the VCS test. Dr Shoemaker has estimated that there's a 90% at least a 90% probability that you are likely suffering from CIRS by just looking at those two screening tools. From there, you would move on to a blood panel. So, there are objective blood blood tests that have been identified to often show up as abnormal in CIRS patients. And so the first group of blood tests are going to relate to the innate immune system, and you're going to see things like MMP9, a marker called VEGF, or vascular endothelial growth factor. Another marker called TGFβ-1, another marker called C4A or C3A. So these are all markers that are heavily or closely tied to the innate immune system, and you tend to see them elevated in CIRS patients. And a second subset of markers is going to look at neuro hormonal markers, and this would be melanocyte-stimulating hormone, or MSH, vasoactive intestinal peptide, or VIP or antidiuretic hormone, or ADH, in relation to what we call osmolality. So those are some of the key hormonal markers that we look at in CIRS. And then there's a the HLA genetic susceptibility test that you can get tested to see if you carry one of these genes. And together with those, so those markers combined with a few other markers that look at some antibody activity to gluten and things like that. So that's about a total of 12 markers that are traditionally assessed. So all of those things combined with a history assessment of the patient. Does this person have exposure to water damaged buildings or other kinds of exposures that could have triggered the illness? And you can see them sometimes. It could be also living like an endemic zone where there's tick borne, or tick elevated presence of ticks that could transmit, you know, the bacteria that causes Lyme disease. So all of that together is traditionally what's used to make the diagnosis for CIRS.

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Kendra Seymour

22:58

Yeah, and we're going to pivot in just a moment to like Lyme and coinfections and tick borne illness and things like that. Because that is I'm super excited to talk to you about that. I know you're doing a lot of work there, but one of the things I want to make clear for people, just especially if you're new to this. That some of the things that cause CIRS, because Shoemaker's **actually list**, it's mold and bacteria. I think even certain spider bites. What else is on that list that can trigger?

CNT

Dr. Christian Navarro-Torres
23:24
Yeah? So you Yeah. So mold was kind of one of the early. Well, actually, the very first toxin was Pfiesteria, coming from Dinoflagellates. These are basically algae that grow in certain lake settings. That was the first discovery. Then Dr Shoemaker started tilting towards water damaged buildings, and that became the focus, because most cases, by far, tend to get sick with CIRS from exposure to water damaged buildings. And in there, you're going to have, like we said, fungi, certain fungal species, but you're also going to have bacteria, and the bacteria that we've identified that cause issues is Actinobacteria and endotoxin producing bacteria. And these can both grow in water damage settings, but they can also be found in settings that are correlated to water intrusion, but it's not just a water damaged building. So for endotoxins, for example, you can have just any exposure to sewer gas smell, wastewater. Anything that's contaminated with wastewater is going to have a high prevalence of endotoxin activity. Actinobacteria could be found in both water damaged buildings, but also in new buildings that don't have necessarily water damage exposure, but there's a dysbiosis in the indoor space, and so you have a high prevalence of certain Actinobacteria that are that we know now are problematic for patients. In addition to that, we have recluse spider bites. We have some ciguatera from fish for certain fish that can emit these certain toxins, and like we said, algae blooms, and it can also include cyanobacteria blooms. So not just right the fisteria that I mentioned. And more recently, we've sort of had covid on the radar, at least as a potential priming event to trigger CIRS, and that's where we see a lot of long covid patients that actually overlap with CIRS patients. And some of the CIRS practitioners will actually argue that long covid patients and CIRS patients are essentially the same patient. They're suffering from the same illness.

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Kendra Seymour
25:35
Yeah, no, that's super interesting. I think we're going to touch more specifically on some bacteria and what you're seeing there towards the end, but let's because you brought it up, and it's a perfect segue into my next question. Is there often, you know, people with CIRS struggle with chronic infections. From things that can be many different types of chronic infections, but like, let's talk Lyme and Babesia and Bartonella. You've said that CIRS patients struggle with that immune regulation. So can you explain what you mean by that and why it makes fighting some of these other infections even harder?

CNT
Dr. Christian Navarro-Torres
26:08
Yes. So I'll start with this fact. If you look at the literature on Lyme disease, what you'll find, very interestingly, is this number, 20% right that we've already talked about, pop up and different literatures, but one of the literatures where you'll see this is in the Lyme literature world, you have a percentage of people who receive a diagnosis, a proper diagnosis for Lyme disease. And they'll go through the standard

treatment, typically includes certain antibiotics, including maybe Doxycycline or something like that. And about 20% of those people do not respond to that treatment. They develop persistent symptoms after undergoing that treatment, and they remain chronically sick. And some people will call these people, these patients, chronic Lyme disease patients. And we think or Dr Shoemaker initially made the connection that these people are most likely CIRS patients. And the insight there is that these patients, yes, they develop a chronic infection, but they are unable to get rid of the infection because they have this, this regulated immune response. And right? So we talked about that connection between the innate immune system sounding the alarms and then the adaptive immune system. What was the term that you use?

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Kendra Seymour
27:37
The cleanup crew?

CNT
Dr. Christian Navarro-Torres
27:38
The cleanup crew, yes, right. So in order to treat an infection in the body, you need your immune system to be properly coordinated, right? When you treat a chronic infection like Lyme or Bartonella or Babisia or anything else for that matter, a big chunk of your ability to recover or treat that illness is not necessarily the antimicrobial treatment. Whether it's herbals or whether it's antibiotics. It's doing that, but then allowing the immune system to come in to manage everything that's happening, right? So that sequence needs to happen for patients in order to see resolution of symptoms tied to the chronic infection and ultimately get rid of the infection or lower to the point where the immune system can manage it. That's the key in treating an infection. Is your immune system, especially your adaptive immune system, coming into the scene and cleaning up everything and keeping everything managed, right? And so we've talked about the immune system being disorganized in CIRS. So if we follow that logic, well, if you have CIRS turn on and it's being triggered because of exposure to water damaged buildings and you're dealing with a chronic infection, it's going to be really hard to get rid of the infection with that dysregulated immune response. So often, for CIRS patients, what they need to do is they have to treat the CIRS first. They have to fix the immune system, and then they start working on treating these chronic infections. That might not be true for everybody, but it's certainly true for a lot of people, myself included. I'm one of these people. I have a Bartonella issue that, you know, I never was able to figure out until late in the treatment for CIRS, but that order of operations was really critical for me in order to start seeing progress with the, on the infectious side.

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Kendra Seymour

29:42

Yeah. And I think even the precursor to that that we didn't talk about was that you want to be in living in a home that promotes health. So yeah, either remediating safely and effectively. And we, I won't get into that and go to our Start Here section at ChangetheAirFoundation.org. We take you through what it looks like. How to find the good IEPs and the good remediators and cleaning and all that. In some cases for people, might mean moving, but that comes first. And I'm glad you brought that up, because I also, I got a tick bite many years ago, and I was fortunate in the sense that I actually had the bull's eye rash, which helped convince doctors. We know that I think it's less than 50% of people right, depending on what study you read, actually gets read, actually get the rash. But that little tick didn't have just Lyme he carried or she, and a number of other things, like Babisia and I was not getting better with standard treatment, and it was super frustrating. And so both, both these things are so near and dear to my heart. So we're going to unpack the that even a little bit more, but let's set some context, because if people are listening, I want them to know that tick borne infections are on the rise, right? Ticks carrying infections are found in all 50 states and really across the globe. So is, can you just give us a line or two about how prevalent this is? Because I don't want people thinking, well, I don't live on the east coast, Idon't have to worry, because that's not the case. So how, what are we talking about in terms of prevalence?

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Dr. Christian Navarro-Torres

31:07

Yeah, so some of the latest meta analytic studies looking into prevalence in the United States suggest that there's somewhere between 14, 15, 16% of prevalence for tick borne disease. A lot of this is heavily focused on Lyme, but we know that there's all these coinfections, right? So there's less literature for the coinfections, but there's a very high chance that if you have Lyme, you have at least one of the other coinfections. Many times in CIRS, you'll see patients with two, three, four, positive tests for these different things. But those are the estimates. There's been, I think, about a two to 3% increase in the global prevalence over the last two decades, roughly speaking, which is actually a pretty significant increase, and a lot of that has to do with changes and climate. Temperature changes is one of those things you know, tick borne or ticks are going to be better able to sort of distribute themselves to different climates when temperatures rise. That's not the only contributing factor. And then there's the question of, how are people's immune systems sort of managing these things? Because a lot of us can have exposure to tick bites and maybe even have, you know, right, the bacteria that can cause a disease, but because our immune systems are healthy, it can keep it managed, and we don't, we never develop symptoms or illness. That's a really important point. And there's actually research showing that there's populations of people that have a high prevalence of exposure, clearly in their bodies, but they have no symptoms, they don't meet criteria for the disease. So these things have been around for a while, but we have to ask the question, what is happening to our immune system? And I think here, the air quality, the indoor

environments have a lot to do with, you know, dysregulating our immune system and us being able to tolerate that. But yeah, so that's more or less where the estimates lie in the US, at least.

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Kendra Seymour

33:22

Yeah, I think that is, is important for people to understand. I did not go hiking. I was in my yard where I keep my grass short, and that's where I picked up my tick. So I would, you know, some people would think, oh, I'm low risk. Well, it's just something that you want on everyone's radar. So let's talk about, I know, when I first went, went to my like, general practitioner for it, like, what are some of the challenges with diagnosing Lyme and the coinfections? Maybe talk to that briefly, and then we can kind of get you some of the treatment and stuff.

CNT

Dr. Christian Navarro-Torres

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And this, again, ties to what we've been talking about, that this regulated immune response that CIRS patients have inherently So, the standard testing that's used for tick borne sentiment is basically what we would call any immunoglobulin or antibody test. We'll see, you know, doctors will be looking for elevated antibodies specific to the bacteria that can cause Lyme disease or Bartonella, that's sort of the standard criteria, other than very clear symptoms like the bull's eye rash, like you mentioned, which a lot of people do not have that, many people don't have. Like, I never had anything like that in my history. So the main problem there is that, again, your immune system's ability to generate an antibody that's part of the adaptive immune response is going to be either disorganized or actually deficient. So what you see often in CIRS patients who have chronic tick borne infections, right? Maybe they've had this for years, for decades, sometimes in their body, and once CIRS became triggered or primed, right, you start seeing a lot of dysregulation. And these infections can start kind of creeping around the body because the immune system is not managing it. So what you see with these patients is you see a lot of what we call false negatives. Meaning they get a negative result in the blood test when, in fact, they have the infection present. And the reason for this is really, or at least, we would argue, or we think, is this dysregulation of the immune system, and in fact, practitioners who are well versed in CIRS and tick borne infections, what they'll do is, they'll start testing over time as they fix their CIRS. And what you'll see eventually, with most of these patients is that eventually you'll start seeing them generating antibodies. So they'll start showing positive results as they fix the CIRS. As they start maybe doing some provocation to kind of push the immune system to launch an attack at the infections, and eventually you tend to see positive bans or elevated antibody activity, which is what we want, at least initially, right? So, so that's more or less the issue with CIRS patients.

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Kendra Seymour

36:24

Yeah, well, and I mean, that is so interesting, like, if the test is dependent on detecting the antibodies in my blood, but my body isn't making the antibodies, it's not going to pick pick up on it. And so I know you talked at CIRSx, where we got to finally meet in person about some of the nuances, the false positives, the false negatives that come along with that. I know that could be you did a whole talk, and that was just like, I feel like scratching the surface before, but I know if somebody just high level was going to get tested for maybe, like, Lyme and coinfections, I know when I went it was like the standard CDC, and there's some limitations there. And it wasn't till I saw a functional practitioner, and I think it was the IGeneX. Do you recommend maybe a more reliable or just a path, if people want to, to rule that out, is there, is there a better testing option out there? In your opinion?

CNT

Dr. Christian Navarro-Torres

37:17

It's a great question. The short answer is no, not necessarily. There are alternate, so there's the, what you said, the standard CDC testing approach or criteria, which, if you go to a Labcorp or Quest, you can ask to do these immuno, IgG, IgM tests for, you know, Lyme. There are other companies out there, like IGeneX, you mentioned it, and Medical Diagnostics Laboratory or MDO, that sort of offer a more, a looser criteria, in terms of what would be considered as positive for a tick borne infection. In principle, that is a perhaps a better place to start when you know you're just trying to assess the landscape and see, is there any evidence here to indicate that something is going on. Very often, even with those tests, you will still see negative results or an ambiguous interpretation of these tests. Certainly initially, when the patient is still very sick, they're still trying to get out of exposure, they're still trying to treat the CIRS at the earliest stages, it's it's sort of to be expected, but sometimes, or very often, actually, patients and these alternate tests will show some trends that would at the very least warrant suspicion. So it's still a good place to start there. And I would say probably the MDL test might be a better option to start with, because it's tends to be more affordable. There may be insurance coverage for that sometimes. So you want to make sure you ask and see if you have insurance coverage. So it's a good place to start. It's a relatively more flexible test, and as you go further along, if you want to really document this, you can move on to perhaps something more comprehensive, which would be the IGeneX test. It has FDA approval now, so doctors might be a little bit more on board with that test. And then eventually you could try to see if you can get a positive test through Quest and Labcorp, as you get better and you progress with the treatment, so that could be one way to go about it. That would be, like, a smart, informed sort of approach.

KS

Kendra Seymour

39:30

Yeah, and I think that's where this, unfortunately, there's a lot of nuance. There's a lot of moving parts for people. It's, I wish it was a straightforward as, like, how a pregnancy test works, right? But it's definitely a little more complicated than that, and that's why I think it's important that people like find a CIRS literate or a Lyme literate practitioner, somebody who really has spent time learning about this, working with patients with these conditions, because they can feel complex. Now before we get into some of the research, because it gets really exciting. I feel like maybe we've kind of, like, I don't want to say, like, just stressed people out a little bit, so let's, like, offer them a little bit of hope. I know you have worked with countless people, or even yourself. Can you, can you share just a story or an antidote about healing or hope or recovery that just to kind of give people something to hang on to if they're in the middle of this.

CNT

Dr. Christian Navarro-Torres

40:23

Yes, I know firsthand how demoralizing and dehumanizing this illness, combined with all the different comorbidities that could show up, how much of that you can experience as a patient, I I'm actually very comfortable talking about my experience as a patient, and I'm pleased. I'm one of these patients that yeah, and maybe this will serve us hope, and I'll maybe touch on one or two other amazing cases. But my entry point into this illness, once I really got into it. I was at a point where I couldn't even wear clothing. I couldn't touch things, surfaces. It was literally I was in some kind of extreme bubble. You know, I lost 50 pounds because, about 50 pounds, I was weighing about 98 pounds when I got really sick, because I couldn't tolerate anything, even water. So I'm in this, I would probably be a reasonable representative of what people would call a hyper sensitive patient. And you know, let's fast forward roughly three years from that. I mean, you saw me. I went to CIRSx. I gave two talks before the month before that, I went to Miami for a conference in Spanish for medical community of Spanish speakers. I'm doing a lot of things that I really thought how am I going to be able to reclaim this? And I know that now I get exposed with things in the environment, and I can tolerate it, pretty well. It takes a lot of effort to kind of take big hits to start kind of noticing, hey, something's off here. I can still read the signs that in real time. That's one of the other things that for me, it's like I would immediately tell this corner of this building, the bathroom, and like, I would be able to figure out what was going on over time because of my hypersensitivities. So and the other thing was food for me, it was as, I mean, at one point I was doing an elemental diet, just powder and water, and that was it. And now I'm actually drinking coffee. I'm eating and, you know, just for reference, there was a point where I would walk past the grocery section of coffee and just walking would be like a disaster. I would get sick for like, the rest of the day. Also, objectively, there were things that were very concerning. I did what's called a NeuroQuant, an imaging report that we actually used to assess the brains of CIRS patients. For someone who was an academic, you know, at that time, was 35 years old. My brain was really, really small. I haven't retested it, but there were all these things that I was like, clearly and

going in the wrong direction very quickly. So that, you know, for me, being able to be able to go out now and do things. I play music, I go to like, this very sketchy warehouse to play music with other musicians, and I actually do just fine. And again, I can travel, I can do a lot of things. And I still, I'm still healing. There's still room for recovery, but it's the difference is just incredible. And I think that's really important for people to, to know that hope is really important. And I've seen it in myself. I've seen it in other patients. Patients with very severe brain atrophy that look like pre clinical Alzheimer's patients in 18 months normalize those, those volumes or parts of the brain that are showing very aggressive signs of atrophy. So I've seen a lot of this, and it's not easy, but it is very possible.

KS

Kendra Seymour

44:16

Yeah, okay, I have so many mixed feelings about everything you said. On one hand, my heart just breaks for everything that you went through, because I know firsthand how it can seem almost like your world is ending, and you are particularly young guy, and to be, you know, really incapacitated. To then you are, you took your pain and you turned it into this passion to figure out what was happening to you and to others. You're bringing it to the Spanish speaking medical community, and like you are just being a trailblazer. And you know, I think there's something special, and I relate so much to someone who went through the experience. That kind of changed the direction of their life, and they're like, I can't change what happened to me, but I'm going to do what I can to help it from happening to others. So thank you for that and all that you're doing, and that hope is so, so important for people to hang on to, and also recognizing that it's not easy, and that that you need to take those steps, and you need to have hope, because people do get better every day, and that's just amazing. So let's talk about some of the cutting edge research that's going on and some of the things that you're doing, because there's some new findings, especially around like endotoxins and Actinobacteria that we want to touch on, and how they may drive inflammation and brain dysfunction and neurodegeneration and all of that. So can you talk about some of the research that that you're seeing and participating in.

CNT

Dr. Christian Navarro-Torres

45:41

Yeah, and I just want to, I'm glad that we get to talk a little bit about this, because I know from the patient perspective, we're suffering. It's hard to understand. But right now, a big piece of legitimizing this illness, CIRS, and and what we call, also, some people will call mold toxicity, or mold illness, or these environmentally acquired illnesses. Right now, the research is perhaps the most important piece. Like there's a lot of legal cases right now that are undergoing with people who are suing a company, or, you know, whatever, and winning those cases, heavily relies on the research and the published research, so I think it's important to kind of have a little bit of awareness around this. And I'm fortunate enough to be involved in a variety of different projects. I work with some doctors individually, including Dr Lauren

Sparks. We're doing some research on erythromelalgia and CIRS. I'm currently working on a publication with Dr Peg DiTulio on colonization of MARCoNS. These are staph bacteria that colonizers patients and contributes to a lot of the symptoms and they need to be treated. So we're working on publishing that. There's a couple other things that also hopefully we'll be publishing at least two papers by the end of the year. And then there's fascinating work by Dr Shoemaker in the last five, six years or so that have really transformed our understanding of this illness. So initially, Dr Shoemaker had this idea that, okay, water damage building exposure, clearly, is making these people sick. He has all these published studies over the years that show very strong associations that really indicated causation, a causal effect from exposure to these environments and changing symptoms and all these biomarkers that we've talked about. Eventually he started identifying brain abnormalities correlated to exposure to water damaged buildings. So that was the second important step, and then eventually he discovered, he and his colleagues, Jimmy Ryan, or James Ryan, is another who's a PhD molecular biologist, discovered what we call the fingerprints of gene expression. So it turns out that CIRS will cause abnormal activity in genes in terms of how active or how under active they become. And there's a test now that they develop, called the GENIE test, that can be used as an add on to the diagnostic to look at patterns of gene expression that can tell you, what are you reacting to? Are you reacting to mold? Are you reacting to something else? And this is where we go into this point, which is thanks to that test and some of the research that Dr Shoemaker and his colleagues have generated, we now know that the primary drivers in most people who get sick with CIRS in terms of what is the immune system reacting to? It's actually coming from bacteria. And we already mentioned and alluded these, it's actually coming from Actinobacteria and endotoxin producing bacteria. So this would be Actinobacteria, would be what we call gram positive bacteria, endotoxin producing bacteria are we called gram negative bacteria, and it's about 42% of patients who do the GENIE test, which is now a very large database of patients. There's 1000s of people now there. About 42 patients. And I think that's actually a bit of an underestimate. I think it's bigger me personally, are primarily getting sick from the Actinobacteria that they're breathing or getting exposed to in these indoor settings that could be water damage, but could also not necessarily be water damage, but highly dysbiotic. And about 28% of patients are getting primarily sick from endotoxins. When we look at immune reactivity tied to mold or mycotoxins, Dr Shoemaker is only seeing about 7% of cases showing primary immune reactivity to those you know, you know, mold and mycotoxins. That doesn't mean that mold is not playing a big role in the illness. It's just that when it comes to the immune reactivity piece that we see in CIRS, that's the correlation that we're seeing. And I'm sure there are ways in which mold and these bacteria interact with one another and will cause, create other kinds of problems that we just haven't been able to figure out. But we know that the bacterial side is extremely important. In my experience, in seeing, talking to patients and helping them that the vast majority of them have Actinobacteria problems.

KS

Kendra Seymour

50:24

Yeah, yeah. I this is, this is also interesting as like, we uncover more and things that we thought maybe aren't the case, or they evolve and change. So one of the things I'm going to ask you to do is maybe to pick, I'm sure it'll be hard, just a couple of your favorite research papers, because we'll link to those in the show notes, and I'm going to put you on the spot, and I'm going to invite you back after your research is published later this year, maybe not the beginning of next year. And you can talk about some of that, and we can dive a little bit more into some of the research and what you guys are finding out. But one of the things I would love to go a little deeper on, and this was part of the keynote too at CIRSx, is the neurodegenerative side of this. So share anything that's at top of mind right now related to that, because I know I have parents who are aging, so I'm starting to think about some of these things. I'm starting to think about my own health, you know, having lived life with brain fog and some of that, it's scary. So what are you seeing there? What are we what are scientists learning?

CNT

Dr. Christian Navarro-Torres

51:23

So when it comes to neurodegeneration, especially like neurodegenerative diseases, like dementia, Parkinson's disease, so this is stepping outside the CIRS or mold illness bubble for a second, there's actually now good literature showing that these diseases are closely tied to exposure to infections, infectious microbes. So just as a reference, back in 2015 there was a study that looked at post mortem brains of Alzheimer's patients, and they looked at the brain regions that were impacted by the illness. Usually it's a hippocampus that's one of the brain regions that's heavily affected in Alzheimer's disease. And what they found is essentially traces of fungal yeast, primarily really candidra, traces in those parts of these patients brains. And whereas in they looked at control brains, healthy brains, and they they found no such things. They were able to replicate that with a second data set. And then there was a second study that came about a year later or so that also replicated. They found these fungal traces in the brains. There's another study that actually found traces of a specific Actinobacteria also, in these brains. And there's actually animal studies. My studies, more specifically, where you'll take like an Actinobacteria species, for example, propionibacterium acnes, which is the bacteria that causes skin acne. We know it's one of the biggest offenders in CIRS patients who are dealing with Actinobacteria. When you inject traces of these bacteria into these brain regions and mice, they basically develop Alzheimer's disease and exposure. And so there's all this study that's now linking all of this and so Dr Shoemaker has found correlations between exposures to especially Actinobacteria and endotoxins, strongly correlated to neurodegeneration, or a profile that looks like neurodegeneration, so brain atrophy, both of them. I would say, or he would say, that endotoxins, high exposures of endotoxins seems to be strongly correlated to a very accelerated path of brain injury or neurodegeneration, so we know so when it comes to the atrophy neurodegenerative profile that these exposure to these bacteria over time can increase the susceptibility to developing a

neurodegenerative disease, and in fact, very recently, Dr Shoemaker discovered fingerprints in this gene activity in the GENIE test that may be predictive of early Parkinson's right? So he's seeing a pattern of gene expression that seems to be predictive of you being at greater risk of developing Parkinson's. We don't know when it could be a couple of years. It could be 10, 15, years down the line, and it's a very early stage of research, and that's particularly strongly correlated with endotoxin exposure. That seems to be the biotoxin, or the microbial category, that seems to be strongly correlated. There's clearly a lot of research that we need to do more. Like this is all very new within the last seven, eight years or so, right? But I think the pieces are now we're starting to create a picture that's telling us, hey, there's there's more to this illness than just mold or fungal exposure. Which is clearly a problem, but there's these other layers that patients need to be able to address in terms of exposure, to really be able to move away from that profile. And the good news is that we can reverse a lot of this with the treatment. We can reverse the brain atrophy and normalize that and get people to feel a lot better. And you mentioned in CIRSx Dale Bredesen and Dr Dale Bredesen, who's an expert in Alzheimer's, he's seeing it from a little bit, from a bigger picture. He's not just thinking about CIRS, but he knows most of these Alzheimer's patients have a CIRS background, right? But he is seeing he's going to be publishing a case study very soon. Where he puts them on this intervention program that he has. People who already have a CIRS, sorry, Alzheimer's diagnosis, and actually sort of get them to massively improve at different levels, symptoms and cognitive functioning, all these things. So I think all of this is treatable. We live in a time where we can treat these things.

KS

Kendra Seymour

56:02

Yeah, and he has a great book, too, people are interested in. Link to the title in the show notes, but I think what one of the big takeaways here, that I think is empowering, is when we understand this, then we can take steps to improve our environment, control our exposure, reduce our exposure, to prevent these things from happening. And you know, one of the things we I know how expensive it is to inspect and remediate your home properly, but the cost of being sick, the cost of long term chronic illness, is exponentially more expensive, you know. And that's something that you know, I think is going to take, as a society, all of us to kind of start changing our thinking around to make the shift. And you mentioned the research, which I do want to do a little plug, because you guys are doing great research. I know you rely on donations and support. One of the things we do here at the foundation is we do, periodically, try to fund small scale research for people like yourself. And so if you're listening and you're like, you know what I love research like this, please consider donating to ChangetheAirFoundation.org, because we then turn around and we find smart people, just like Dr Christian Navarro-Torres, and we give them money so they can figure some of these things out and help all of us. Because one of the things, and you mentioned the legal case, and I talk with a lot of the lawyers and the doctors sitting in on those, and they rely on your research. They they rely on, you know, those case studies as entry points to then build more research, and that's how they're winning cases. And so, so it really is all connected, and it's going to take all of us to figure this out. So

CNT

Dr. Christian Navarro-Torres

57:35

Do you mind if I add one more thing that I forgot to say? So, in terms of actionable steps, right? If you're in this category and you're concerned about the brain, the very first thing that you should probably consider doing if, if you have the resources, is to do a NeuroQuant. It's an it's a software program that could be added on to a standard MRI scan, and it will generate a quantifiable assessment of different brain regions, and this is what we use to look for patterns of brain abnormalities in CIRS patients. I'm actually very this is, I mean, I'm my background in neuroscience kind of biases me to pay a lot of attention, to this, but I think it's really important for people to understand that, CIRS, is about the brain. It starts in the brain. It's an inflammatory response. It starts initially affecting your brain, and eventually, if you don't treat it right, it can turn into this brain issue. So doing the NeuroQuant will give you a good sense of where you're sitting in that and then you can track if treatment is really helping you, and not just in terms of symptoms, but also in terms of preventing, right? The possibility of you developing something like a neurodegenerative disease. And you the nice thing, and I want to do a quick plug in here for the company Cortechs.ai because now you can get an MRI anywhere in the world, and then you could there are a couple people, ourselves included, where you can send the raw MRI images and we can generate a NeuroQuant report for you. It used to be the case that only certain clinics would have the NeuroQuant and then you'd have to do everything through them. But now it turns out that you can go to essentially any MRI facility in the world, regardless of whether they offer their NeuroQuant or not, and you can just get the raw images and send it to someone like us, for example, and then generate a report. So I just want to use this as a tool to empower patients right to kind of be able to assess this on themselves, because I do think it's very important, and when you see normalization or recovery in the brain, it's extremely empowering. Yeah, so I just wanted to plug that in.

KS

Kendra Seymour

59:52

No. And I thought, I know if you talked about it, maybe it was your Instagram or newsletter recently, or not that long ago. You talked about seeing some before and after of the brain of a really sick person, and then this incredible healing. And I love when you can see stuff like that in black and white. Did you want to speak to that at all?

CNT

Dr. Christian Navarro-Torres

1:00:10

Yeah, this is a case of a patient that I knew very well and was helping sort of survive, because it was in this very hyper sensitive, crazy, hypersensitive category where it's like, you know, you can't even just basic things, right, like wearing clothing and just basic things like that are not available. So I saw this person roughly over a period of 16 months, and this person did put a lot of emphasis getting a clean environment.

Very, very, very, very strong about cleaning, but not just for mold. It was also doing cleaning regimens for Actinobacteria, for endotoxins, and then doing the Shoemaker protocol, n addition to a few other things, there were some add on things that were done that we think were very important for her brain recovery, because her initial NeuroQuant was really bad for her age, it was just massive cortical atrophy in the brain. So the part of the brain that you can see from pictures from the outside, all of that was severely atrophied, and then in about 16 to 18 months of treatment, especially the last step of the Shoemaker protocol, we think was very critical, which is intranasal administration of a peptide called vasoactive intestinal peptide. This is the peptide that has been shown to normalize brain volumes. So maybe 10 to 12 months into that, combined with a few other add ons treatments, we saw this complete. Basically, we couldn't tell the second NeuroQuant from a healthy person. It looked virtually very, very, very normal. And I was kind of shocked, considering where this person was coming from.

KS

Kendra Seymour

1:01:53

Yeah, that is like a big old dose of hope, if you needed one today. So we are, we are so over time, and I am going to hold you, and I hope you'll come back, because I know questions from listeners just wanting to know more about your personal story. I know I want to pack more about your research, but until that time comes, how if people wanted to follow you learn more about the work you're doing? How can they get into contact with you?

CNT

Dr. Christian Navarro-Torres

1:02:16

Yep, so we are in social media. Our primary social media pages, Instagram, if you just search, CIRS Lab, that's the name. But we're also on YouTube. We have a YouTube channel. We're on Facebook, and then we have a website, cirslab.com, you can learn more about the things that I'm doing. We have memberships for like patients and practitioners. If you're interested in that, you can find out more about that there. So those are the main outlets where you can maybe get to know about me and also get in touch with us.

KS

Kendra Seymour

1:02:48

Awesome. And we're a link to all those in the show notes, so you don't have to hunt for them. And we'll try to make it easy for you. Thank you so much for being here. It's always a pleasure when we chat, and I truly appreciate you taking time out of your day to kind of share some of this insight and expertise with us. So thank you.

CNT

Dr. Christian Navarro-Torres
1:03:02
Thank you so much, Kendra.

KS
Kendra Seymour
1:03:04
And for everyone else, if you found this interview as informative as I did, and I know you don't want to miss any more like this, please head on over to ChangetheAirFoundation.org, and sign up for our newsletter. Or if you know someone who needs to hear this, share this interview. Like it. Click that follow button help us reach more people. Thanks so much. We'll see you next time you.