THE SPECTRUM OF HEALTH
PODCAST

Podcast Session #58

Bitten: Lyme's Impact

With Kris Newby

Dr. Christine Schaffner speaks with Kris Newby, an award-winning science writer at Stanford University and the senior producer of the Lyme disease documentary, Under Our Skin. Together we talk about her book, Bitten: The Secret History of Lyme Disease and Biological Weapons*, misdiagnosis and underdiagnosis in Lyme disease, and a journey to Lyme recovery.*

For more on Kris*, visit* www.krisnewby.com

Dr. Christine Schaffner: Welcome, everyone, to the Spectrum of Health Podcast. I'm Dr. Christine Schaffner, and today my guest is Kris Newby. Kris Newby is an award-winning science writer at Stanford University and the senior producer of the Lyme disease documentary Under Our Skin, which premiered at the Tribeca Film Festival and was a 2010 Oscar semi-finalist. Newby has two degrees in engineering, a Bachelor's degree from the University of Utah and a Master's degree from Stanford University. Previously Newby was a technology writer for Apple and other Silicon Valley companies. She lives in Palo Alto today. Kris and I are going to be talking about her book, Bitten: The Secret History of Lyme Disease and Biological Weapons. Welcome, Kris, I'm so excited to have you on the podcast today.

00:53 Kris Newby: Well, thank you very much for having me on. I appreciate it. I just really want to get the word out about Lyme disease, so thank you.

01:02 CS: Absolutely. I wanted to have you on the podcast for so many reasons, and of course, to talk about your wonderful book Bitten that we'll dive into. This topic is a big part of my passion and journey, I've been doing this work for about 10 years, and it's really rewarding, but it's heartbreaking work. Every patient's story is just how you said--to hell and back. These patients go through so much and there's so much confusion. They often experience not being heard for way too long, I think, before they get a proper diagnosis and the right treatment. And even treatment can be challenging, so I really appreciate you sharing your journey and story so that we can make sense of what we're seeing and why we have a population that's struggling with Lyme, as it is really an underlying cause for so many chronic health conditions. So thank you for your work.

02:01 KN: Thanks, thanks.

02:02 CS: Well, let's just dive in. Obviously, your personal journey prompted you to write this book, Bitten, and as I already mentioned, you had this journey of "to hell and back," and again, that's what I see every day. How did Lyme impact your own health and how are you doing today?

02:25 KN: Well, my husband and I went on a family vacation to Martha's Vineyard in 2002. I was in my early 40s, we had two middle school boys, and we went to Martha's Vineyard, and unbeknownst to us, we were both bitten by ticks. And then we got back to California, and it was a really horrendous journey, a year undiagnosed with two tick-borne diseases. We saw 10 doctors and it cost probably $60,000 dollars in various tests. We were both unable to work. It was a year undiagnosed and then it was probably four to five years of treatments before we were 100% back to our old selves, and I'm happy to say that today, I'm great. I mean, it's been maybe 10 years since I've had symptoms, so it's a happy story that I hope gives hope to people who are in the middle of their Lyme journey right now.

03:29 CS: Yes, I think that's so important, Kris. Especially when patients start this journey, it can be so overwhelming and so scary. The symptoms that an average Lyme patient experiences can really make them feel like they're dying--the intense anxiety to the neurological symptoms, to the pain, to everything in between. A big part of my work is just calming people down and giving them that encouragement that yes, even though this is really hard, there is an end to this, and it's absolutely possible to get better. That comes up a lot. Patients ask me, "Are you sure I'm going to get better? Is this really going to end?" And so, I really am so grateful you're sharing a story of hope and of

healing because that is a big message we want to get out there. So let's just dive in. You obviously wrote this book, Bitten. It's a lot about your personal journey, as you were undiagnosed for one year. Why do you think there is such an issue with misdiagnosis or under-diagnosis? What are we dealing with, with Lyme in that way?

04:46 KN: Well, first of all, when you're bitten by a tick, you can receive multiple pathogens which create sort of messy, not textbook-like symptom sets. I think the doctors are focused on one disease only, Lyme disease, so whatever you show up with might not match what they spent 15 minutes on in the 80s when they went to medical school. Like with my husband and I, we both got Lyme disease plus Babesiosis, which is a Malaria-like parasite and that's a really strange set of symptoms. People in California aren't familiar with Babesiosis symptoms so that's one of the reasons that it took so long. But the other thing is, I'd like to say, I'm writing an essay on this now--Lyme is the disease that time forgot. Early screening tests are really no better than a coin toss, as to whether you have the disease or not, and it's really based on this antibody technology that was invented in the 40s, right after World War II. It doesn't really measure whether you have the active disease in you, all it measures is if you've been exposed to the disease and is your body creating antibodies in response to that infection which could be happening now or could've been in the past.

06:14 KN: So, I think our modern doctors are really used to thinking, "Oh, this is a gold standard test." But they don't know, it's like 30%-50% accuracy for this screening test, and you might really have Lyme disease, but maybe they test you in the first month where it's not really reliable and they say, "Well, it's

negative. You don't have it." And that sends people down this Alice in Wonderland hole of specialists and testing and our profit-driven medical system. It just starts to add up.

06:49 CS: Absolutely. I think that's such a good point, that you say "it's the disease that time forgot" and that even here in 2020 when we're recording this, there's still so much to be desired for testing. Do you have any opinions of some of the other tests out there or some of the tests that you feel are really needed in order to make a more accurate diagnosis in the beginning or just to help people get diagnosed more quickly?

07:27 KN: Definitely. The thing about Lyme disease, which is a Borrelia, a spirochetal bacteria, is we're finding out now that there are multiple strains in different parts of the country. There's a second strain, which is called Borrelia mayonii and we don't even have any test for that. The tests that are used across the nation are for Borrelia burgdorferi, which was found around Long Island and Lyme, Connecticut. And so that's coming up with false positives. That's just one of the problems. And then we have the co-infections. The test I think we need is a test that uses modern DNA microbial techniques, so we're actually measuring if there's a live organism in you. And then we also need to look at it as a real-world situation, not that one tick is going to deliver one germ, but let's say there can be a couple disease-causing pathogens that are transmitted to you. So let's take one drop of blood and run it through maybe the top 10 tickborne diseases if you know you've been bitten by a tick or if you suspect you have. And in that way we can treat the germ with the proper drugs really early, with a minimal amount of fuss, and then you can go on with your life and never know the bullet that you dodged.

09:05 CS: Absolutely. I've been doing this 10 years, and we have the antibody tests, and there's one lab that we've used over the years, DNA Connexions, it's more of a PCR test, looking for actual DNA of not only Borrelia but also the co-infections. We developed at Sophia Health Institute a method of provocation because part of the issue is, which we'll get into later, how Lyme and co-infections are not just living in the bloodstream, they can hide and create symptoms in the connective tissue, in the fascia, inside the cell and the brain and the heart, and that's why sometimes we are not able to always demonstrate the presence of DNA just on a blood test. So, we developed a provocation test, it was basically a urine collection after people would get either lymph drainage or deep body massage or ultrasound just to really stimulate that movement of microbes from the connective tissue into the lymph and where they eventually make their way to the kidneys and are excreted via the urine.

10:12 CS: We were actually quite surprised with how many positive tests we would see when that test had gotten into motion, and then the lab had to change their parameters--there were probably all sorts of pressures on them. That is something we saw. And then there's the lymphocyte test, where you're looking at the actual immune system reactivity--is the bug there, and then what is the immune system doing to the bug? And how can we support people and treat it appropriately? So I think there's still so much to be desired, Kris. Again, I would have hoped even in my 10 years that we had just more affordable testing, more streamlined testing, and more accurate testing as well. Part of the problem is that when you have Lyme, your immune system gets very compromised in a lot of ways. So even looking for an immune response is not always the most fruitful way of seeing if the immune system is mounting a defense against an infection. I digress a little bit, but these are

things that I'm always contemplating with Lyme testing. I really hear your point with this.

11:30 KN: Yes, and the immune system provocation, I've heard, is a very successful approach. I think that's smart because I have been talking with a researcher at Standford and she was saying that the Lyme disease spirochete gets out of the bloodstream as soon as possible. It doesn't want those killer cells after it, so as soon as it can, it drills into immune-protected sites, in your joints that have scar tissue or inside your brain, so I think that strategy is a smart one.

12:07 CS: Yes, and I think we have a lot of room to perfect that and to make that the next standard. I totally agree. Kris, with that being said, I want to also highlight your story, which again, is one of hope. We want to talk about all of your research and all of your journey of learning about why Lyme exists and why we're dealing with this as such a pervasive root cause of so many chronic illnesses. I also want to take a moment to hear about what healed you, because I know people who might be struggling with Lyme and would love to hear how you recovered. What was your journey to wellness and what really got you the help and your health back?

13:02 KN: Well, when we showed up in July back in California, we got the runaround. My husband and I got sick on the very first day, a week after we got back from Martha's vineyard, which was number two in the US for Lyme disease and number one for Babesiosis. Yet, all the California doctor says is, "That's a rare disease. We're not going to even burn the money on a test for that." Or, "Oh. We think that's a virus." Or, "For you and your husband to both

get Lyme disease would be like winning the lottery," and now, I'm thinking, "Wow...that's a lottery you really don't want to win."

13:39 KN: So then you start making your way to the infectious diseases doctors. And they've been indoctrinated with this scenario or this paradigm where a lot of hypochondriacs say that they have Lyme disease, they want a label that's convenient, and they really are just needy. So our first infectious diseases doctor said, "Well, you know... " They gave us a round of Doxycycline, we'd had the disease five months then, and that cleared it up. Then a month later, or a few weeks later, the symptoms came back worse than ever. I called up the doctor and said, "Oh please." Almost in tears. "Please can we have more of those antibiotics. That was the first thing that worked in four months of being really, really sick."

14:30 KN: And he goes, "No. We can't treat based on your reaction to drugs." You have to follow some scientific paper rather than how your patient feels, which is not very empathetic at all. Then he goes, "Well, I think what we're seeing here is a psychosomatic couple's thing." Where he was basically saying, "Your husband is a busy businessman and you're wanting attention, so you're faking this disease and your husband's picking up on that."

15:00 CS: Oh my God.

15:01 KN: So it was just so ridiculous. Finally, we made our way to an academic medical system. The nice thing about that is these infectious disease doctors, who are hard to get to, it's hard to get to these specialists and they're super expensive, he and his fellowship student ran every test known to man on us and for the first time in nine months, we got a positive. I got a positive

on the Lyme ELISA which is antibody test. My husband didn't test positive. And then they said quickly, "Well, that's all we can do for you." And they fired us. I came back and I called them out. I said, "Hey, I just looked at the CDC website and it says if you test positive for this ELISA antibody test you have to do the next step of the test." And they were really embarrassed but I think they knew that and they just wanted to ditch us as patients.

16:01 KN: Because the department at that time had an unwritten policy--"most of those people who say they have Lyme are really hypochondriacs. We don't want to waste our time with that." So they tested the second test, and that was positive too. But they fired us. Well, I was just devastated, just in tears because neither of us were able to work. Our function as human beings at the time--we had brain fog and pain, gut pain, crushing, crushing fatigue, neurological problems like you can't believe. And we had just been kicked out of the best hospital on the West Coast. So then we went on the internet and it turns out 24/7 there's all these Lyme patients trying to help other Lyme patients. There's this whole community. And very shortly they connected us with a Lyme doctor who was really good in our town. She'd been trained at Stanford, but she was also an integrative doctor, so she used a lot of principles that naturopaths do, about detoxifying and supporting your gut biome. She immediately ran the right test for us, and we came back positive for these two tick-borne diseases and then we started our healing journey, which is another ordeal, as you know.

17:35 CS: Yes. Thank you for sharing that. Basically by the time you got bit by the tick in Martha's vineyard, how long did it take you to actually get the first positive Lyme test, that ELISA test. How long of a period was that?

17:54 KN: That was at 10 months. And then it took us another two months to find the right doctor, get into the office, and then get a treatment. So it was a year from the bite to actually getting treated. Which is short. I think, as far as I hear all the time.

18:16 CS: I know. That's even more heartbreaking, that that's considered a relatively short amount of time. And then how long did it take you, Kris, from the time of that diagnosis and working with that integrative doctor for you to feel like you had recovered your health?

18:33 KN: Well, six months...After six months, my husband was able to work pretty well. He wasn't 100% cured, because we hadn't really discovered the Babesia. The antibody test didn't work in the beginning because our antibody complexes were all gummed up and it wasn't showing up on the test. So to feel like you were half-human, it took my husband about six months, and me a year. But to be functioning at 90%-95%, that was pretty much five years for both of us. It wasn't like we felt crummy the whole time. It was that we would go on combos of antibiotics for a month and a half, and then wait and see. Then if the symptoms came back then we would try another combo. It was just being orchestrated by our doctor who'd treated a lot of people successfully, so she had a strategy that she followed.

19:37 CS: Thank you so much for sharing your journey. You had a clear tick bite, right? So you had a clear event and it took you a long time to get diagnosed and to get better. But what about all the people who come down with Lyme who might not know of an actual tick bite or have potentially some other route of transmission? Can you educate us on that?

20:03 KN: Well, we actually didn't know we had been bitten by ticks, but we knew we'd been in an endemic area for ticks. So we didn't know, which was one reason they didn't test us. I mean, I was bitten in my hair, underneath my hairline in the back of my neck, so it's not a place I can see very easily. My husband never was sure where his tick bite is and we half think maybe it was sexually transmitted, but we just don't know. There'd been no studies on that but we just have anecdotes from Lyme physicians that say, "Wow, there do seem to be a lot of couples who both have it." And certainly, spirochetes have been seen in vaginal fluid and sperm. There've been studies on that, but it doesn't prove that it's transmitted in that way. But the point is, we need to do studies on this because it's really important.

21:05 CS: Absolutely. I appreciate you bringing up the sexual transmission. That comes up a lot in my practice with questions about that. And again, people are wanting to be safe and protect their partner and all of that. I agree, I think there's so much more research needed. I'm still surprised at how limited the knowledge base is to guide physicians from that research point of view of the sexual transmission. But absolutely we know it's sexual transmission and then maternal-fetal transfer as well. So there are these other routes. We call Lyme a vector-borne illness, in that it's not just from ticks, right? There could be other vectors that co-transmit both Borrelia and co-infections, like mosquitoes, fleas, and other potential insects. Do you have any other thoughts on that before we move on?

22:07 KN: The message I'd like to put out is we just need a lot more research dollars for this disease, especially considering it's the largest vector-borne disease in the US and it's impacting millions and millions of people. Right now, I think, it's funded at the level of leprosy, which just doesn't seem right.

And there have only been four randomized treatment trials. With our current recommendation for treatment, which is Doxycycline for adults, there's a 15-20% failure rate for that. And if we're talking about a disease like AIDS, well, with that big of a failed treatment rate, a lot of people are going to die. So, we just need more research on this.

22:58 CS: Yes, absolutely. Can you comment, and we can start our dialogue about why there are not more research dollars spent on investigating Lyme disease? What can you share about that? What are your thoughts at this point?

23:19 KN: Well, I was a senior producer on this documentary on Lyme disease, which was Under Our Skin. And I did the deep dive on conflicts of interest associated with Lyme disease. One thing that I found after some digging is that, if you look at the people that write the infectious diseases guidelines for diagnosis and treatment, a huge percentage of that panel of 12 had patents on test kits or vaccines in the early days. So, we're beyond, I guess, the patent there. But what that did was create profit motive to fight off other competitors because they own these early patents. And that crew that writes the guidelines, they continue to file patents. For example, for Borrelia mayonii. So rather than having a test that would screen for multiple Borrelias, they're patenting individual tests, which is more money into the system and it takes longer for patients, so there's more chance of them falling into the chronic part of the disease.

24:33 CS: It's like there is a whole overhaul that needs to be done and motivating the industry to do these tests, which seems just so backwards, right? When you're on the frontlines or if you're struggling that that is what has to

create change. The film Under Our Skin, Dr. Klinghardt was a big part of that and I know so many of our patients have found that documentary to be helpful. And you really started the movement. I remember I was at naturopathic school when I saw Under Our Skin. Even as a naturopath, I think we had one afternoon lecture on Lyme disease. Still, the training is so limited in medical schools, and even alternative medical schools. We still have a long way to go in properly educating physicians to diagnose and treat. Kudos to you for that film. That was a really big, I think it caused a big change in awareness.

25:44 KN: It was the first major media piece to show the patient point of view. Before then, if you wanted to know about Lyme patients, you read about it in The New England Journal of Medicine or JAMA. And that presents a picture where it's over-diagnosed and a lot of these people who say they have Lyme disease are just suffering from the aches and pains of daily living. I think the film made a lot of people cry.

26:16 CS: Oh, yes. Absolutely.

26:18 KN: Because also they realized there are people like that, and me. And the people who didn't have Lyme disease said, "Oh, I didn't realize it was this big of a problem," and that these are the symptoms. Because what I found is the symptom set in the medical literature was just totally different than what people were experiencing in the field. And the other thing is during the three and half years of filming of that documentary we interviewed Andy Abrahams Wilson in Sausalito who is a very talented filmmaker. He's the director and owned the production company. The problem is nationwide now. There have been cases reported by patients in all 50 states. So, I think that was an important message to get out.

27:09 CS: Oh, absolutely. I'm grateful that you all did that work and came together. How many years now since the film came out? What year did, Under Our Skin come out?

27:24 KN: 2008. And then it was an Oscar-semifinalist in 2010.

27:29 CS: Wow.

27:29 KN: And I think people still watch it all over the place, streaming.

27:33 CS: When you look at it now being 2020, are you surprised at where we are? Did you think when you were making the film that we'd be at a different place now?

27:51 KN: I am very sad that not much has changed. I mean, about a year ago my book Bitten came out and I did a talk on Long Island, which is really ground zero for the Lyme Disease outbreak. It's been 40 years since we first noticed it, and for my husband it's just too painful for him to hear the blow by blow of the Lyme, the efforts to get attention for Lyme patients. But he went to that all-day presentation and he walked away shaking his head saying, "Nothing has changed in 10 years." Now I get, since I'm semi-famous in the Lyme world, I get maybe one connection a week from a patient and they tell me these stories and it sounds just like my story from 2002, 2003 and it just breaks my heart. It makes me angry too because of the injustice of it, that this disease has been neglected and it's so preventable. There would be no Lyme wars or Lyme controversy or all this carnage if we had a test that worked. Not

even a perfect test, just a semi-reliable test that's better than a coin flip. It just makes me angry.

29:14 CS: I think anger is a very healthy emotion. I think anger, sadness, all the grief that you see. I mean our Lyme patients are some of the most amazing people who've been through so much and they're so courageous and determined with what they go through to recover their health. If you're listening out there and you just imagine your life turning around and upside-down sometimes overnight, sometimes it's a gradual process, and really not being able to do what you love and end engage in life. So I see a big part of my job is returning people to life, for them to be able to live a passionate and purposeful life. That's what we're all here to do. And so, yes, I hear you. For your book, Bitten, it obviously took, I'm sure, many years, maybe five years, I think you said, to write. You really connect the dots between Lyme Disease and biological weapons, and this has been something that has been seemingly controversial, to try to understand that connection and make sense of why people are suffering with the illness and how they're suffering. Can you start to share the story of the connection between Lyme disease and its origin as a biological weapon?

30:48 KN: There was the first clue that Andy, the director, and I realized showed that there may be more to the story other than, "Oh, all of a sudden there was a random mutation of the tick and this new virulent disease appeared." I mean, that's the party line, right? We were trying to get a government expert to be interviewed for the film, and this was around 2007, and NIH Agency refused to let us talk to any of the experts. So we said we'll just fly out to Montana and interview Willy Burgdorfer who discovered the causative agent of Lyme Disease in 1981. So when we were there, and Willy, at the

end of the interview after we turned the camera off, he said, "Oh, I didn't tell you anything" with a glimmer in his eyes. There had been rumors swirling around about Lyme disease being caused by a bioweapon, but that wasn't what the documentary was about and nobody was willing to talk.

31:49 KN: So that seed was planted there, and then, like a year after the film was done, another filmmaker friend says, "I got Willy to confess to say that he recognized one of the organisms, when he was investigating the Lyme outbreak, he was on the team trying to figuring out why all these people have been getting sick in the '70s around Long Island, Connecticut." He got Willy to say to the camera that he recognized something from the bioweapons program from back in the day. So, that was the start. And really I was tired of Lyme disease, I wanted to move on, I had a really good job as a science writer at Stanford, but it just felt irresponsible to keep going and ignore something that could be true. So that started my five-year investigation into really asking the question, "Was there a bioweapon there that caused the outbreak?" Willy never said it was Borrelia burgdorferi, he said it was another microbe that he had recognized. That was five years of research, I interviewed Willy's history and had gotten some access to some of his original lab notebooks that he had donated to Utah University. And then I went out and talked to him. This was shocking news to everyone, but Willy was in the US bioweapons program weaponizing fleas, ticks, and mosquitoes for years at Fort Detrick, the offensive program. And so that made his confession all the more believable. So then I did research on our entomological warfare program, and I found an eyewitness who said he dropped poisoned ticks on Cuban sugar workers, in I think 1962, as part of the plot to oust Castro. And then I sort of looked backwards. The year they said Lyme was discovered was 1981, and I said, that's not when people started getting sick. So I started reading all the

literature on what happened 10 years before that. And it turns out that the first Lyme cases were identified in 1968 in Connecticut. And, oh, by the way, there are also two other really freaky new tick-borne diseases that all of a sudden appeared around 1968. And so then you say, "Hey, where are we weaponizing fleas, ticks, and mosquitoes with dangerous germs in them?" And there were a lot of open-air uncontrolled tests, so could this whole thing have been caused by irresponsible weapons designers doing experiments where they deployed them in foreign countries?

34:56 CS: Yes, there's so much here, Kris, to unpack, and we're recording this in the time of COVID. We're friends with Judy Mikovits, and she talks often about her work at Fort Detrick and what goes on there. I think maybe somebody who's listening out there might wonder, "Wait, what do you mean? Why does the US even have a biological warfare department?" Can you share with people why that's a reality, and just give them some context for that?

35:33 KN: Yes, so the quick history is, after World War II, we captured some of the German and Japanese soldiers and realized they had really extensive bioweapons programs, insect-borne too. As Americans, I'm saying we, Americans, we picked their brains on what they were doing, the Russians were doing the same, they've sort of started this biological weapons race and I guess it just kept on escalating. My book goes into some of the more outrageous experiments done on unconsenting people in America. And then there was an accident in Utah with nerve gas and a bunch of sheep died. Nixon was president at the time and he says, "No more bioweapons." And so by '72 officially all bioweapons programs were supposed to be shut down. Now in the labs, it was allowed to do defensive bioweapons research. So right now officially

we're doing defensive bioweapons programs. But, as long as we have dangerous microbes growing in a petri dish or a flask or a test tube, it wouldn't take that much to make it an offensive program. I mean it's believed by experts that the Soviets and the Chinese have continued their offensive bioweapons programs, but I didn't really look into that.

37:11 CS: You could have a whole another book probably, Kris, on that right now. Okay, so that gives us some context. When you map out your research and look at the founder of Lyme disease and Willy Burgdorfer and his discovery of the spirochete Borrelia burgdorferi which we named it after him as a causative agent to Lyme, how do we tighten up that connection that he has? He worked in the bio-weapons program, he worked on weaponizing ticks and mosquitoes and fleas, and then here he finds the spirochete that is responsible for creating Lyme disease.

38:01 KN: Well, he was a cog in the wheel of the biological weapons program. What he did was, he put very dangerous disease inside ticks in the '50s. Whatever showed up in the late '60s, I believe it was part of their airborne weapons program. By the late '60s, they thought putting germs inside ticks was difficult because you're trying to keep two living things going so they could be spread out over a city or a battalion. So they started growing microbes, some of them can be carried by ticks in large vats and then freeze-drying them, so they could be made into particles that would float in the air, like the anthrax powder. And they did a bunch of open-air tests. I think Willy thought, and what I think, is that some of these aerosolized germs, possibly Rickettsia virus, got out into the population through the CIA tests and at the same time the army was testing with the spread of ticks on the eastern seaboard, specifically near Norfolk, Virginia. So they were mass-producing ticks

by the hundreds and thousands. They were irradiating them, making them radioactive, so they could see how far they would go with a Geiger counter.

39:33 KN: This was done perhaps so that they could drop it on enemies and know, okay, in a year the infected ticks spread so many miles, through birds, bunny rabbits, deer. So I think it's a series of unfortunate accidents where the army released these really aggressive lone star ticks, they're man-biting, they have eyes, they could stalk their prey, they spread this red meat allergy. They released them by the hundreds of thousands on the Atlantic bird flyway. They went all up and down the east coast. Plus you had these open-air test particles, and I think maybe it's a mixture of those accidents that caused this freaky outbreak. Maybe Lyme disease is a mixture of Lyme disease plus some weaponized thing. So, in my book, I don't prove 100% that this happened, but I lay out the evidence. I say what we know, and what we don't know, and I say, scientists, I've gone as far as I can go not accessing all their secret documents and not having a gene sequencer. Lyme scientists, take it from here.

40:48 CS: I think you've done an amazing job doing that and painting this story and picture where you have a lot of these factors coming together. I agree we have to look at this because on some level, as you experienced with your own health, Lyme disease can be very hard to treat even when you get the diagnosis, right? And so it makes us think, what are possible mechanisms and reasons behind why this is more of a virulent strain or a virulent species of spirochetes, or even the co-infection piece. In your research, how did you make sense of the widespread co-infection diseases that we see? So when we talk about co-infections, many of you already know, we're thinking of

bacteria, also viruses, sometimes even other pathogens that get co-transmitted alongside typically Borrelia. This can be Babesia, or Bartonella is very common. You also mentioned Rickettsia. How did you make sense of the co-infection piece of the story?

42:18 KN: Well my turning point on that was when I interviewed Willy Burgdorfer in 2013 and he said, "when I was analyzing the blood of Dr. Allen Steere" (this was in the late '70s, '78, '79) he says, "I looked at the blood, and I saw this unknown Rickettsia." Rickettsia is a really, really small bacteria that goes inside a cell and behaves more like a virus. It goes into the cell, reproduces, explodes the cell, goes on, and does that over and over again. The common name for that family or the most popular name is the Rocky Mountain Spotted Fever. That's the most deadly tickborne disease in the US and the US government had an active weaponization program for that, and they were figuring out how to deploy it as an aerosol from planes. It would be very deadly.

43:17 KN: They also worked on some viruses, which would be chronic incapacitating agents, so you could spread those from a plane and there would be no way to trace it back to its origin without DNA analysis. It is a perfect scale-out weapon because it would chronically disable a whole population with a disease that looks a lot like chronic Lyme, what we say chronic Lyme is. So, I guess that made me realize through that whole experience with Willy and once I did background research that it could be the co-infections [that are so worrisome]. Maybe Lyme disease isn't the worst thing that's making people chronically ill, maybe it's Lyme disease plus this weaponized co-infection of Rickettsia virus and it's just undetected, there's no tests for it and doctors aren't looking for it. That could explain why 15%-20% of the people who are

bitten by a tick have a lot of trouble getting better. I have to say that the US Army...I mean, when we went into the archives, they did pilot studies on Brucellosis, Brucella that causes Brucellosis, Bartonella, and Rickettsia, like I mentioned. They even tried to put rabies inside of ticks, so there were a lot of experiments to get down to a list of maybe the eight go-to bio-weapons.

44:48 CS: Wow. It makes sense that it's in the Northeast and on the East Coast, and then now we're seeing this everywhere as you mentioned--with Under Our Skin, that movement has gotten this recognized in the fifty states, but also people can get infected in fifty states. I've seen some interesting insights in books and stories of how this has really become ubiquitous in our environment. Does any of your research point to why it spread in the ways that it has?

45:39 KN: So if you look at the places where bio-weapons were tested, there was Fort Detrick, Maryland, that was the headquarters. They did a lot of open-air tests there. Willy has told another person that they released ticks there. Then you have Plum Island right off of Lyme, Connecticut, off of Long Island, and that was an anti-animal bio-weapons program and there were a lot of tests there where ticks or birds, or lizards, or deer could have picked up diseases and spread them. You have the tick releases in Virginia and in Montana and Willy would always say there's no such thing as a clean-clean tick. So were those ticks really clear of other diseases? I mean these are all scientific questions people might be able to prove, but I'm just presenting facts as I've seen them. Then we had the sort of mastermind for the biological program after World War II, Ira Baldwin, who at some point was the Dean of University of Wisconsin at Madison. He managed a lot of open-air tests in the

Wisconsin-Minnesota area, and that's the first place where Lyme disease showed up, or the thing that we call Lyme disease now.

47:10 KN: And then we had an airborne program and shipborne program run by the Navy mostly. And there were experiments with bacteria off of San Fransisco, Catalina Island, up in Canada, and there were tick-borne diseases released to places like Alaska off Hawaii in the Pacific Ocean. There's just pockets of weird diseases right now and I think it really helps for us to look at the spread of this disease with the biological weapons program in mind because it would explain a lot of things. You know, any epidemiologist could be treating like, "Oh it's just climate change and it's humans moving into forests and overpopulation of deer." This is just another factor that needs to be folded into epidemiologists' analysis.

48:10 CS: Yes, such a great point and of course, after hearing your conversation today, just an obvious place to look. Everywhere you're mentioning, I'm thinking of patients I have in those areas and so that absolutely raises a lot of questions. I believe Willy died of Parkinson's, right? Parkinson's disease is that correct?

48:38 KN: Yes. Complications due to Parkinson's.

48:38 CS: Was he ever tested for Lyme disease or was that ever looked at? Because you know our view of most neurological illnesses is that Lyme or co-infections can be a huge trigger for those. Do you know if he was ever tested?

48:58 KN: Well, he thought he had Lyme disease and I read his NIH workers comp form. He says the year after he discovered Lyme disease, he was in cleaning infected rabbit cages and the urine splashed in his eyes and he believed he got Lyme disease. He was certainly very sick after that. His coworkers tested him, there was just an argument whether Willy really had Lyme disease. But he had what looked like five Lyme rashes on his armpit and he felt like maybe his Parkinson's could have been caused by that infection. I know he also had Rickettsial infections when he was in charge of Rickettsials at Rocky Mountain Lab. So who knows? I know he asked Dr. Steere for advice too.

49:56 CS: Yes, it's those connections. I'm making them, that it's not far fetched to see that was a trigger to his Parkinson's. What a wild story. And you already mentioned that he was probably a cog in this whole operation. When you were connecting with him, did you feel his intentions were good or bad? What were your thoughts?

50:29 KN: You know, he was a complicated, interesting character, and personally I liked him. I thought he was an amazing European-heritage gentleman, a really meticulous scientist, you know, so, to me what was interesting is his life story arc. Primarily the book Bitten is a biography of Willy, how he was a young ambitious Swiss-German researcher who came to Rocky Mountain Lab and immediately joined the bioweapons program, and he was very excited about his work. As he got older, I think he realized the implications of what he was doing and the gravity of it and he started feeling guilty. And, you know, towards the end of his life, especially when he was suffering from what may or may not have been Lyme disease, he felt like, being the guy that he

is, maybe he wanted to set the record right and level the playing field so, you know, he left several journals and he told his story.

51:38 KN: He had advanced Parkinson's but his brain was all there and he knew what he was saying. He was not making stuff up and certainly the documentation that I collected corroborated what he was saying, that he believes that there is a bioweapons origin for several microbes in the Lyme area. He never said Borrelia burgdorferi was the weapon. It could have been, he just wasn't saying it, but it looks like a Rickettsial or a viral coinfection that may have been the chronically disabling thing that we call Lyme disease now.

52:17 CS: Wow. It's so amazing that you were able to connect with him personally as you were going through all of this research. And, with everything that we've gone over and in light of your own personal journey, Kris, how as a clinician and speaking to other clinicians or potential patients out there, do we need to think of treatment differently, given the potential bioweapon origin of Lyme and co-infections?

52:52 KN: Well, I remember talking to a bio-security, bioweapons specialist who's in DC and he was lecturing to Stanford students, I was sitting on it and he goes, "Well, doctors are so confused because it's not a disease, it's a weapon." Which is sort of depressing, but 50 years later you have to hope that the virulence has dissipated since the release originally happened because it...A good parasite does not kill its host, right? But what we really need is the government to declassify these experiments. What did you release where, and what was the research that you did behind releasing these germs? Because if they weaponize any germs they would have tested vac-

cines, and they would have done animal studies. So, one of the main messages of the book is, let's have a congressional investigation over the released stuff because we'll save billions of research dollars if we know what was released when and what the research was to back that up. There're a lot of things keeping people from releasing that.

54:12 KN: There's horrendous legal bills and lawsuits to deal with just as we've had to do with Agent Orange and the Tuskegee Experiments, which were all designed by the same people that thought of these bioweapons. But the Cold War is over. It's time that we look forward. Let's look at COVID, there's flaws in the public health system that were invisible to us but not to Lyme patients until we had a really rapidly-spreading virulent disease. Now, these hairline cracks in the system that all Lyme patients knew about are breaking the dam.

55:04 CS: Absolutely. I know this is such a challenging time on so many levels, but I agree if there's a silver lining to it...more and more people can wake up and to have this awareness because only from there can a change happen. I think there's so many aspects about our healthcare and our recognition of how we treat people with acute illnesses but also with chronic illnesses. I think you're right. I think this is a huge opportunity for us to really reinvent a better way. I'm an optimist in spite of it all. I always try to look at that piece as well.

55:52 KN: Yes, I am too. I'm looking at the COVID disaster as an opportunity to fix the things that are broken. We need a rapid direct test for Lyme disease and then COVID. We need to not take a wait-and-see attitude on treating and not be so stingy with antibiotics, and more research, and better tracking.

56:24 CS: Yes, I was going to ask, what do we need, so that's perfect for the winding down of our conversation. I absolutely agree with all this, and I think you're right. I think, the research, the funding, is so big. And I think about the clinicians on the frontlines who treat Lyme and we don't learn this in school. We learn this from our patients, of course, there are wonderful organizations out there that are educating physicians currently. But I always think, how much better equipped and how much better able would we be to serve our patients if there was a research arm really helping us perfect our treatments, and perfect our testing, and putting these pieces together? I envision a future where, "Hey, can we have our version of the Mayo Clinic for the illnesses we treat?" So, we'll put it out there, Kris, I know you're really working hard still to make that vision a reality. And I really applaud you for your work and your continued dedication. There's so many people that you're helping and serving that really don't have a big voice in creating the change. So, thank you.

57:42 KN: You're welcome. And thank you for the work you do. I know it's never-ending and challenging.

57:52 CS: Yes, it's all of the above, but really rewarding. Right? I know your doctor was probably so thrilled to see you on the other end of your journey, and that's why we all do this. So, Kris, if people want to learn more about your work or how to support you, obviously, we will write a link to your website and your book, Bitten. I absolutely recommend it. I have it on Audible. I let go of the idea of reading books, I'm an auditory listener and with my schedule, I listen to books now. How can people learn more about your work and support what you're doing right now?

58:39 KN: The website krisnewby.com has vintage photos from the book, and information. You can order a book through HarperCollins Publisher or on Amazon. And the paperback comes out at the end of June. I know that a lot of Lyme people have vision issues so I do think Kindle, large-print, and the audiobooks help a lot of Lyme patients.

59:03 CS: Awesome. Well, thank you so much for your time in this really insightful conversation and I so appreciate the work you're doing, Kris. So, thank you.

59:13 KN: Thanks a lot, Dr. Schaffner. I appreciate the time to spread the word.

59:17 CS: Thank you. I hope you enjoyed my conversation today with Kris Newby. Please check out her website, krisnewby.com, and I hope everyone is staying healthy and well during this time.