



## INTERVIEW: Lyme – the first epidemic of climate change

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*The following is an edited transcript of a Feb. 8, 2018 interview of Mary Beth Pfeiffer, author of the new book, "Lyme: The First Epidemic of Climate Change." The interview was conducted by writer Bill Densmore at a Lenox, Mass., restaurant during a visit by Pfeiffer to The Berkshires.*

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*Q: Why have you written this book?*

PFEIFFER: I'd covered Lyme disease for several years and then thought about writing a book about it. Because I knew enough to know that it was a very, very serious problem. But when I started writing the book I realized I had a great deal to figure out about Lyme disease. I had a great deal of science to read.

I read 300 scientific papers, or thereabouts, for my research. I had to figure out the flaws in the testing and what the science said about that. I had to figure out the new science of persistence and how we're figuring out that the live spirochete can survive antibiotic treatment. I also had to figure out what were the flaws in the American approach to Lyme disease and I had to sort of organize all that into one narrative that would be approachable to the general public.

The myths of Lyme disease are in there, the over diagnosis, the easy-to-treat, the "it's hard to get" -- that's all in there. And so what I did was I put together all of that reporting that I did over a period of years and built on it by diving deep into the science. This is the view that we have of in America and here is what's wrong with it. That's what the book is about.

*Q: Why did you get on the Lyme beat and what is the passion you have for sticking with it?*

PFEIFFER: A lot of people ask me that, in particular at gatherings of Lyme patients and the advocacy groups and conferences. Because people can't believe that an investigative reporter has finally taken an interest in this topic. I started investigating in 2012 simply because I'm an investigative reporter and I investigate topics that are of interest to the community where I live and in the Hudson Valley there's virtually no family or group that has not in some way been touched by Lyme disease. So I was aware it was there, it was growing and I heard a couple of horror stories along the way.

What I found, and the response I got is what made me stick with it. I found a disease that was woefully mismanaged by the government and by medicine. I found a disease that was misunderstood by the public in general and by frontline doctors. I found of course, I think we all know this, many, many people who contended that they had continuing symptoms of Lyme disease even after treatment but they were sent from doctor to

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doctor, 10 doctors, 15 doctors and told you don't have, you have something else, you have rheumatoid arthritis, you have fibromyalgia. So that was just a little bit of the picture that emerged of to me as an investigative reporter -- and what kept me going.

There's one other thing that kept me going as well and that was the response by the Lyme community, which was clamoring for somebody to take a serious look at this. They had in droves come to the *Poughkeepsie Journal's* website and shared our stories. They were shared around the world and posted in Australia and all over the country. So it is not just that we were getting traffic to our website. It was that it was an indicator that something was wrong and we need to keep following this.

*Q: They don't intend to be dueling but as a practical matter there are two dueling medical groups thinking about whether Lyme can persist and what to do about it. Can you explain briefly those two -- they even call themselves "camps," which is quite remarkable from a patients' point of view. Explain how that has arisen and whether, as you step back at a 20,000-foot level, you have no stake in either one. How do you see finding center ever occurring here and is that likely to happen? Because patients are left in the middle.*

PFEIFFER: We'll I'm hoping that may happen, that my book will frame a larger discussion of because I have framed it from the 20,000-foot level. This is what it looks like. You are correct. We have two dueling models of care. We have the one from the Infectious Diseases Society of America, (IDSA) and we have the one from the International Lyme and Associated Diseases Society (ILADS). IDSA and ILADS for short. And the problem is that the IDSA model is the one that has prevailed for many years, at the expense of any competing model of care. And the IDSA model basically says that Lyme disease is the following -- it can be diagnosed, somewhat, rather easily, with some exceptions, it can be treated into three or four weeks of antibiotics, and the spirochete is killed. End of story. There is a recognition by the IDSA and by the CDC which endorses, or has endorsed, the IDSA guidelines, of something called Post Treatment Syndrome -- which is a misnomer to many. It is a constellation of symptoms. People stay sick after Lyme treatment. There is very little doubt about that.

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Now on the other side, the ILADS group basically would content that there's a great chance that the people who have these ongoing symptoms have continuing infection. And many ILADS doctors treat with long-term antibiotics. But at the same time while they want the freedom to give more antibiotics -- and many of them have been hampered from doing so, have been brought up on professional charges by the way, they also acknowledge that it is not the panacea. It often does not solve the problem, it keeps it in check. It has to be provided -- that is antibiotics in the longterm -- with a number of other medicines to treat perhaps co-infections like Babesia, like Bartonella. And it also is part of a larger treatment milieu in which they do things to support the immune system and to make you stronger and to detoxify. It is a rather complex field of medicine.

*Q: It strikes me from what I have learned about it so far that a lot of the complexity and longterm nature of it tends to be left at the wayside by traditional medicine and traditional insurance, meaning that there is a whole subculture of physicians who are in this world who don't take health insurance and so there is a significant financial issue for people who believe they are suffering from some kind of persistent impact from Lyme? How does that get fixed, because it is a challenge for patients?*

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PFEIFFER: Well there is a simplistic view of it, as I said. The IDSA model is pretty cut and dried. Hence, it makes it much easier for insurance companies that have endorsed these guidelines, which have denied claims based on the guidelines to say we don't have to pay for 2-3-4 months of long-term antibiotics, in particular intravenous antibiotics. Because No. 1 they are rather expensive and we'd rather not have to pay and, No. 2, we have the IDSA on our side. So that has put these Lyme-literate doctors in a real fix. They cannot bill to insurance companies because the insurance companies are largely going to reject their care. But the other thing is that many don't try to bill to insurers because they could be flagged, they could be reported to state professional disciplinary boards because of the way they are practicing care. In other words they are giving out long-term doses, rounds, of antibiotics that contravene the prevailing standard.

And there is little doubt that even though there are these two schools of thought in medicine of how to treat Lyme disease, and that the two schools of thought are based in science and are based in published guidelines, in the case of ILADS, their guidelines are on the national guidelines clearing house, a federal website. IDSA's guidelines have been on there for a very long time but they are now updated and they are being rewritten, so they're not even on there. But while you have these two valid approaches, based in science, it is the IDSA's that have prevailed, largely because the CDC has endorsed that approach. The approach has been based on articles that have appeared in the top [medical] journals in America and that carries a lot of weight in America and allows the insurance companies to do what they do and say, 'We're not going to pay for your care.'

*Q: What do you think is the impact of a class-action lawsuit filed recently in a federal court in eastern Texas, by a couple of prominent plaintiffs' law firms which names as defendants a bunch of individual doctors and health insurers. Talk about that a little bit. What dose that mean, what was the apparent reaction of the CDC and do you think that will begin to change anything?*

PFEIFFER: The lawsuit that was filed against the IDSA and others is a really startling development in the evolution of Lyme theory and Lyme thought and Lyme treatment. It came out after the book was done. But I discuss some of the issues in the book certainly that are presented in the lawsuit. And just to sum up what the lawsuit contents. It's against the IDSA, as a society, it's against eight members of the society, eight prominent infectious-disease physician researchers, many of whom authored the guidelines of the IDSA, and it's against eight insurance companies. It may be seven physicians, something like that. It contents they conspired.

The lawsuit was filed against the IDSA and against a core group of physicians who have authored the guidelines themselves as well as much of the research that has been published in clinical and infectious disease journals and well as others. And it's also filed against seven or eight insurance companies. It's filed, by the way, under the RICO act -- Racketeer Influenced and Corrupt Organizations Act -- which is amazing in itself.

*Q: It allows even mail fraud to be brought in if there is an alleged conspiracy that involves anything through the mail?*

PFEIFFER: And I believe that's in there because it contents that monies were paid to various physicians to work on behalf of the insurance companies in denying claims. And all of this, I must add, must be proven in a court of law. These are just assertions.

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*Q: But also, obviously one impact of this is that the people who have been sued are going to have to be much more careful about what they say and where they say it going forward.*

PFEIFFER: Well, that's the typical advice you get from a lawyer when you are in a lawsuit, especially in federal court.

*Q: So one collateral result of this is going to be for the wagons to circle even more than they have, right?*

PFEIFFER: Well, that's a good question. I asked the IDSA: Would the new guidelines still be published in the spring of 2018 as was forecast. The guidelines were last updated in 2006. So they are very out of date. They are supposed to be done about every five years. They have been in the process of being revised.

There have been lots of meetings. And the IDSA's response to me was yes, that will be done, they will be released on time.

*Q: So what happened with the CDC website after this lawsuit was filed and is there any connection?*

PFEIFFER: I would imagine that there is some connection with what happened on the CDC's website, which was basically that the longstanding link on the website to the IDSA guidelines, in the context of how do you treat Lyme disease was removed. Now that doesn't mean that the CDC has a whole new approach to Lyme disease and that it's endorsing the ILADS approach. In many other ways and turns of phrase on the website you will see material that reflects IDSA views on how to treat, how the tests work, how the treatments work and of the danger that is contended is posed by giving patients longterm, especially intravenous drugs.

*Q: In the book, you tell stories of specific patients. But what I'd like to ask you to do is provide a composite view of the typical, if there is any such thing, process of discovery, sorting out, treatment options and outcomes for Lyme patients. Can you provide two or three typical examples that worked out well, the jury's out, and somebody is still struggling after years.*

PFEIFFER: I think over five years of studying, I faced the gamut of examples -- including my own. I had a Lyme disease rash before I published my first story, but, interestingly *after* I began my research. I was very fortunate, I went to the doctor, the doctor recognized it, the doctor correctly said, you don't need a test, you have Lyme. And the doctor treated me. Her prescription was doxycycline [antibiotic] for three weeks. I asked for an additional week based on the information people had given me about the really significant dangers of letting this go and get out of control. On the side of being very cautious, I asked for that.

But then you have a spectrum of ways patients are treated when they think they have Lyme disease and they go to the doctor. I've heard stories of people who go and they have the Lyme rash and they are told, we don't have to do anything about that, you don't have Lyme disease, or it will clear up by itself, or it's a spider bite.

There are many, many misconceptions even among doctors about in particular in places where Lyme disease is growing and just coming to the fore. Maybe in this area, in the Berkshires, they are a little bit more savvy about it, but even so in the Hudson Valley, I heard of a lot of people who were misdiagnosed even when they had the rash.

But the other thing is, according to the CDC's own numbers, 70 percent of people get the rash. That's based on 150,000 cases in which they found 70 percent actually manifested the rash. Well, that's best case, because those are the people who were treated and who's cases were reported to the CDC. Even in that cohort of people, 30 percent of them did not get the Lyme disease rash.

*Q: And the rash comes out typically some period of time after a bite, right?*

PFEIFFER: It's usually a couple of weeks that it manifests.

*Q: So even if you get the rash and you are treated then, the spirochete has been nosing around in your body for two weeks without treatment, right?*

PFEIFFER: Well, yes. But it tends to stay there and disseminate in the weeks after. It starts moving around the body.

*Q: So one of the more typical responses from doctors that I've experienced and heard about is to say: 'OK, you have a tick bite. You removed the tick. It appeared to be engorged. Take two doxycycline for a*

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So I would not put a great deal of stock into the single-dose doxy study. The ILADS basically content you should get 20 days of treatment if you have been exposed in that way, potentially.

*couple of days and you're all set, and do that right away. What are the arguments pro and con for that protocol?*

PFEIFFER: The single dose "doxy" study, because it is two pills basically that you take once, is open to great question. There are competing studies that show that is really not the case that we can stop Lyme disease in its tracks, as the *New York Times* reported when the study was published. There are studies on mice who were exposed to ticks and then were given these short courses to basically see what happened. In animal studies, the single-dose doxycycline study has not held up.

There's also flaws in the study itself. In speaking to scientists, basically I'm told they defined whether you got Lyme disease basically by whether you got the rash or not. But we know only 70 percent of people get the rash. So that is a significant omission. And the paper itself admits that this may be a reason to question its findings. So I would not put a great deal of stock into the single-dose doxy study. The ILADS group basically contents you should get 20 days of treatment if you have been exposed in that way, potentially.

*Q: So a physician who is accustomed to practicing around the single dose doxy . . .*

PFEIFFER: Any many are.

*Q: . . . [T]here is a good-faith argument they make that we don't want to be prescribing antibiotics willy nilly because we don't want to be contributing to the social ill of potentially creating an antibiotic-resistant strain of something. On the other hand from the point of view of the individual patient, it is not for the patient to worry about that. It is for the patient to worry about not getting to Lyme and also to worry about not having an adverse reaction to the particular antibiotic you are being asked to take. Talk about the ethics and the efficacy and the professional quagmire of overuse of antibiotics vs. underuse of antibiotics in the case of an individual. It is deeply challenging.*

PFEIFFER: There is little doubt that in our society there is an overuse of antibiotics that are prescribed for people, just in case kind of thing. They are vastly overused in agriculture in livestock maintenance. The problem is that the line seems to have been drawn with Lyme. It has not been drawn with other diseases that require longer courses of antibiotics -- like tuberculosis. With tuberculosis you can be on antibiotics for 18 months for that. There are other things -- urinary-tract infections -- you may need a long, long time to get over it.

*Q: There are some doctors who see some similarities between syphilis and Lyme and they point out that historically the long-term treatment for syphilis is long-term antibiotic use.*

PFEIFFER: And the very key parallel between syphilis and Lyme disease is that they are both caused by a spirochete and the syphilis spirochete is well recognized to persist in the body and be very difficult to kill and to require long courses of antibiotics. It is also acknowledged to cause dementia. Something like a quarter of the people in mental hospitals in the United States 50 or 60 years ago were people with syphilis. And we do know Lyme disease as an aside leads to many mental health issues -- to depression, anxiety, to things that affect our brains, our functioning, our behavior.

*Q: In your book do you address the question of how settled the science is of whether the spirochete can morph into different forms that get behind the blood-brain barrier and can sit there and wreak havoc to the brain. Is that all theory, is it fact, is it unsettled science?*

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**But in the last five years, [some science] says that the Lyme spirochete can survive some of the best antibiotics that we have in our arsenals and this is based on test-tube studies, it is based on animal studies.**

PFEIFFER: There is a great deal of science that has emerged in just the last five years, some of it pre-dates that period. But in the last five years, it says that the Lyme spirochete can survive some of the best antibiotics that we have in our arsenals and this is based on test-tube studies, it is based on animal studies and it is based to a very small extent on one human study where people with Lyme disease who were treated to it and were then exposed to clean ticks in a very, very small number of cases. And I believe in one or two cases the ticks became infected from these people who had been treated.

So there really is a growing body of science and it is becoming accepted. It is coming out of Tulane, Northeastern and Johns Hopkins, that the kinds of antibiotics that we have been using on are not strong enough to kill the so-called “persisters”.| That they go into hiding in some way. They have these nifty little ways of evading the antimicrobials -- biofilms is one of the ways, changing shape, round bodies. I don't go into that in any great detail in the book. But I do discuss a lot of this emerging science that has struggled for a long time to break through and finally is. And we can talk a little bit about that, too.

*Q: Why is it starting to break through now?*

PFEIFFER: Well, I think the sheer weight of it, the fact that it has been replicated in these three major institutions. But researchers from those institutions as well as from affiliated with many other universities and so forth have almost to a one told me of how difficult is to get published, or has been to get published, when you have a view of Lyme disease that is outside the mainstream. They are held to a much, much higher standard. They are told there is no such thing as chronic Lyme. They are told we know that antibiotics, we should not be giving people more antibiotics. And the reason that they are told these things, that their papers are rejected or made to be rewritten is that very strong IDSA model and the IDSA researchers have on the landscape. Just to continue this. The reason they have such a strong hold is because they sort of got there first, they defined for what it is. They were published in the *New England Journal of Medicine*. They were published in the other very high-level journals. And they accrued a lot of power.

The are held to a much, much higher standard. They are told there is no such thing as chronic Lyme. The are told we know that antibiotics, we should not be giving people more antibiotics.

*Q: Who are they, can you name some of them?*

A: They are the authors of the guidelines. Gary Wormser is one of them. Ray Detwiler would be one. Allen Steere. Robert Nadelman, who was the first author on the single-dose doxy.

*Q: Have you been able to talk to them for your book?*

A: For the most part, they do not speak to me, they will not speak to me.

*Q: Why is that? Do they consider you biased?*

A: Well, they consider me to be presenting a view of Lyme disease that they don't adhere to. I have to say there are exceptions. Ray Detwiler for one is very open and willing to discuss the science as he sees it. But others either do not answer my calls or tell me through a spokesman, as Dr. Wormser did and Dr. Nadelman did, that they will not speak to me. It's a real shame.

And it's not even that I am obliged, it is that is the right thing to do and the best thing to do. I want to know all the sides so I can draw a legitimate conclusion. So the fact they won't speak to me is a problem. It's a problem. It is bothersome. But it is not a game stopper.

*Q: How does that make you feel as a journalist?*

PFEIFFER: Well, a journalist has to try really hard to get the full story. As a journalist I am obligated to make sure I do not leave any stones uncovered in the story. And it's not even that I am obliged, it is that is the right thing to do and the best thing to do. I want to know all the sides so I can draw a legitimate conclusion. So the fact they won't speak to me is a problem. It's a problem. It is bothersome. But it is not a game stopper.

There are many things that have been written that tell me exactly what they think. Scientific literature in particular. My book has 300 scientific citations. It is not a footnoted book, it is a book that is written in a way that is very accessible to the public. But its based on science but the science is pointing to a different view of Lyme disease . And this view contends or upholds the connection that Lyme may not go away. That the Lyme spirochete does stay active in the body or returns to some state of activity in the body after supposedly curative antibiotics. And its time for that to break through. And as I said, that view has been stymied by the great power of the side that contends that Lyme is easy to diagnose, easy to treat. And one way that they have been able to uphold this view for so long -- I mean the original guidelines were published in 2000 -- is by repeating their contentions in article after article and having others also follow them in doing so because they are respected and accepted because after all they published in the New England Journal of Medicine and the Clinical Infectious Disease and so forth.

For example, there was a study published by Allen Steere, the very prominent physician who first discovered Lyme disease in Lyme, Conn., in the 1970s. And he wrote in 1993 about the over-diagnosis of Lyme. And he basically went back and looked at records of doctors who had diagnosed Lyme, retested all the patients -- or the samples, I'm not sure which -- and concluded that many of those people diagnosed with Lyme did not in fact have it. OK, that is premised on two assumptions. The first would be that the tests work. That we can tell from the two-tier test that the CDC endorsed, that whether you have Lyme disease or not. It is also premised on,, well that well if you were diagnosed with Lyme disease, maybe the doctor did so because clinical judgment came into play, the doctor saw you symptoms and said this person needs to be treated.

After that single over-diagnosis study was published there were, I counted in the literature, 34 more papers on the over-diagnosis of Lyme. It became a mantra. And many of the researchers who did the study did sort of a quick and easy look -- did exactly what Steere did, look at the people, look at the samples, and use the two-tier test and when we perform this the way we do it there weren't as many people who were positive. So doctors got the message -- be careful, do not over-diagnose it is a bad thing to do. And so doctors became scared of Lyme. But then when you look at under-diagnosis of Lyme, I believe the number was, I found four studies of underdiagnosis of Lyme.

And it's one thing to perhaps treat someone with a short course of antibiotics in case they have Lyme disease, or believing that they have Lyme disease -- maybe they, false positives occur. But what about not treating someone who does have Lyme disease and it was a false negative? Because we do know that the tests fail in a certain portion of cases. They fail a lot early in the disease, less later in the disease but there's still is a portion of people for whom they do not work. The upshot of not treating those people, of underdiagnosing, is much more grave, I would content, than of treating some people.

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*Q: And particularly so if you believe that Lyme is persistent or pernicious in a number of ways. If you think there is no such thing as persistent Lyme or post-Lyme treatment syndrome, if that is your frame of reference, then undertreating Lyme doesn't seem like a big deal to you.*

**PFEIFFER:** That's true. But yet, I think mainstream medicine does accept that if you allow Lyme to advance untreated that it is a more serious disease. That is accepted. What they say, the mainstream view is that after treatment if you still have symptoms then it isn't because they don't believe in chronic Lyme.

*Q: One of the memes in your book is to think of what's going on as Lyme as an example of a climate-change related phenomenon. Talk a little about that.*

PFEIFFER: Well there is some really interesting science about the movement of ticks around the planet. And what these researchers have done is to go back on the archival data banks and see how many ticks were on this mountain in the former Czechoslovakia in 1960 and how far up the mountain did the ticks live. We know in 1960 they went halfway up the mountain. Comes along now a scientist in the last five or 10 years who does the same study and lo and behold we find the ticks are much higher up the mountain and we also have weather data showing its warmer, there is less snow, there's more ticks living at this altitude.

So they are climbing mountains, as I say in my book. They are climbing latitudes. They are moving into Canada. Canada is a new frontier for right now. They are where we were about 20 years ago. And beyond the ticks moving north, and ticks have always been moved around by birds and birds have dropped them here and there but now the ticks are surviving. But beyond the ticks moving into Canada, for example, you also have the white-footed mouse who is also able to live much further north than it could. So there is a lot of science showing there are more ticks, in more places, in many, many countries.

This is a problem in China. There was one study in China about residents in the suburbs of Beijing and it said this was a huge problem of underdiagnosis of Lyme disease among residents. It was written in a way that amazed me for the Chinese which is a pretty guarded government and culture. But it was written in a rather alarming tone. And it has shown up in many other provinces in China. It's in Russia, where they also have documented the growth and movement of ticks. It's in South America. It is certainly in many, many states of the United States. And again we are having trouble with counting cases and in cases being documented and reported because there's not a great awareness of the danger.

*Q: So let's switch gears away from the science and the dispute within the medical profession and macro issue of climate change, and focus on the patient for a minute. But before we're all patients, we're all people who live and many of us enjoy living outdoors. Do you see Lyme as necessitating a change in the way we enjoy the outdoors? And what will be the impact on the tourist and outdoor industries if that's the case?*

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PFEIFFER: That's an important question, Bill. I wrote my book from the perspective of Lyme being the first epidemic of climate change for that reason. It is an environmental issue. It has changed our relationship to nature. I used to let my kids run around in a field with grass up to their thighs, roll around and have lots of fun. And we have to look at a child now in that situation and be fearful that some little critter is going to climb up the short sleeve or under the pant leg and do some really serious health problems. And there are many children I do talk about some cases in my book of children who have lost their childhoods to Lyme disease .

So, I think that yes we do have to be very guarded in our interactions in nature in the modern world where Lyme disease exists. And it is a great part of the modern world. Because there are a billion ticks out there, and they are just waiting to latch on.

*Q: So you can't just say, I will do a tick check and take a shower at the end of the day and everything is going to be OK?*

PFEIFFER: You can say that and I'm not saying don't go out in the field or walk on the trail. You have to be very, very vigilant though in how you interact with nature. When you're walking on a path, don't brush up against the tall grasses, because that's where the ticks are. They just climb them in the beginning of the day and they just wait for a passing mammal. it doesn't matter if it is a deer or a mouse or a groundhog or

whatever -- or a human being. They'll just latch on. So just be careful where you go -- stay in the middle of the path.

I also talk in the book about permethrin-soaked clothing and shoes. It is very, very effective. Shoes and socks in particular. Just wearing socks that have this chemical soaked into them. You can buy it pre-made or just buy a spray that you put on your shoes and socks. It lasts many washings.

*Q: What about the argument if you are not partial to chemicals in your life? What do you say to somebody who doesn't want to put permethrin all over their body, how do we know what the long effects of that are going to be?*

PFEIFFER: Well, I am one of those people who hates to take out a can of insecticide or a jar of insecticide and kill anything. I've never used anything on my lawn. My lawn is filled with dandelions and filled with poison ivy on the edges. I can really appreciate that. But I have concluded that this is such a serious risk that it poses such grave danger to children in particular that perhaps we need to rethink our use of certain substances. And there have been studies done on permethrin and by and large they show it to be quite innocuous.

*Q: So do you use it yourself?*

PFEIFFER: I do. But if I'm going to just take a quick walk in a field -- I have a field across the street from my house and I talk about it quite a lot in the book and we've mowed a path around it, but I stay in the middle of the path. Then I won't put on permethrin-soaked socks or shoes and I'll just be careful. But the problem there is the dog wanders into the grass and comes out with ticks.

*Q: What if you have a dog, what do you do?*

PFEIFFER: I don't recommend anything in particular for dogs in the book. But my dog uses this collar that last several months, that is quite economically and it works very well. There are other products where the dog will eat a little biscuit once a month and that works very well. And there is a vaccine to protect dogs against Lyme disease but the positive thing about these other approaches to preventing ticks from latching is it is an anti tick mechanism. The chemical in the collar or in the biscuit gets into their blood. The tick bites them and it kills the tick. The tick falls off and doesn't stay on long enough in most cases -- there's always an exception -- to infect.

**Well, I am one of those people who hates to take out a can of insecticide or a jar of insecticide and kill anything. I've never used anything on my lawn. My lawn is filled with dandelions and filled with poison ivy on the edges. I can really appreciate that. But I have concluded that this is such a serious risk that it poses such grave danger to children in particular that perhaps we need to rethink our use of certain substances.**

*Q: Back to the human patient. We've talked briefly about how to deal with the outdoor challenge. So let's say you get a rash, or you removed a significantly engorged tick and it's tested positive and you go to a doctor and your doctor says, two doxycycline pills and you're done. What can you do as a patient -- do you change doctors, do you argue with the doctor, do you put the doctor on notice that you think they're practicing malpractice? What do you do?*

PFEIFFER: Well, I've had this argument with my own doctor. And anytime you bring up Lyme to a doctor, the doctor says: "I know about Lyme disease ." It's kind of giving this attitude that: "I'm fully informed, I know what I'm doing." One doctor said to me, "People see Lyme disease everywhere." So that's sort of the attitude -- that "it is overdosed" attitude. And I had a long talk with my primary-care physician about the single-dose doxy approach and I presented to him the flaws of the study. And if you read my book there is a very concise, maybe one page, not even, explanation of what's wrong with that study and why it shouldn't be relied up as a standard of care. And the other thing is it is one, single study, and it has become the standard of care. Science usually wants a study that repeats before they accept it as a standard of care.

*Q: And what did your doctor say?*

PFEIFFER: He listened. I was rather insistent. But I don't know if it changed his behavior as far as dealing with other patients. I hope it made him think.

*Q: Well, if you got a tick bite and either it tested positive at a lab or you got rash or other symptoms a few weeks later, what would you expect your doctor to do? What would you do if you had a rash or an engorged tick which lab tested positive for Lyme or a related disease?*

A: If you have a rash, you have Lyme disease and you will I hope be diagnosed and will be given several weeks of doxycycline. It's a done deal at that point.

*Q: What if you remove an engorged tick of the species that typically carries Lyme in an area of country where is prevalent and your doctor says two doxies. Do you argue about that, what do you do?*

A: In my book, you can say there is science that disputes the single-dose doxy approach. And by the way many patients also know about that. They know that if they get bitten I have to go to my doctor and ask for that treatment. That's what my doctor says is part of the problem -- patients are demanding it. This is part of the framing of Lyme disease in America, it's been framed in a certain way that it is easy to head off -- the tests work, it's easy to treat. People at all levels have been fed this image of Lyme disease.

And its generally the people who've had the horrible Lyme experiences who know that is not a correct view of Lyme disease. There is another view of that is much more insidious, much more dangerous, that have cost children weeks, months in school, can really cripple and disable people. It can lead to death in some cases. But become Lyme has been framed in this way we also have very little research as to how to treat Lyme disease when it gets beyond the point of the rash.

*Q: There is a California-based nonprofit called LymeDisease.org. I believe they are starting to collect epidemiological information. The government's not doing that, but they are. Can you talk about why that's not been done by anybody before and why hasn't asked for federal money to conduct such data collection?*

PFEIFFER: The reason that has been underfunded and that many of the answers we have about protracted cases have yet to answered is again is because of how it has been framed. It's not chronic, according to the mainstream view. It can be treated. It's hard to get. It's overdiagnosed. This is all part of the myths of Lyme disease and that is why this research has been stymied.

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On the other hand, you do have nonprofit organizations such as Bay Area Lyme Foundation and the Cohen Foundation and Global Lyme Alliance which are funding scientists to do ground-breaking research that the government won't fund. LymeDisease.org has come up with a terrific idea. It's called MyLymeData.org. They've enrolled about 10,000 people who have had Lyme disease. And they ask them all about their case, how many doctors did you have to go to? How many miles did you have to drive? How many days of work did you have to miss? Were you disabled? What were your symptoms? What were you diagnosed with before you were diagnosed with Lyme disease? So it was something in the order of the famous Framingham Heart Study where they tracked may people over a long period of time to see what the impact of heart disease was.

-- END OF INTERVIEW --

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