Navigating Lyme Advocacy: Fight The Quiet Epidemic Transcript

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Introduction to Lindsay Keys and The Quiet Epidemic

Hello, everyone. My name is Dr. Richard Horowitz. I am the co-host of this DrTalks for the Healing Lyme Summit. And it's my great pleasure today to introduce you, Lindsay Keys, who's a filmmaker who did a recent wonderful documentary, The Quiet Epidemic.

So Lindsay Keys is a filmmaker, photographer and writer based in the Hudson Valley, New York, where I am living. And she's co-director and producer of this recent award winning documentary, The Quiet Epidemic.

The film screened at more than 20 film festivals, had a limited theatrical run across North America, and ultimately premiered on Amazon Prime and Apple TV.

iTunes in 2023. Where you can see it and Lindsay is now co-leading the quiet Epidemic's impact campaign alongside a team of impact producers and strategists who leverage the power of filmmaking for change.

So, Lindsay, it's a great pleasure to have you here. You and I have known each other for quite a long time. Why don't you share with the audience who you are, how you got into this, why you made this documentary on Lyme disease.

Yeah. So I was bitten by ticks. Growing up. I did not know that all of my mysterious illnesses were related to tick bites until my mom became sick. And doc, you saved her life, so thank you for that.

As always. And then she saved mine. So my mom was the one who helped me piece together the fact that all of the symptoms I was having were related to what I thought were previously cured infections.

They were ongoing infections. So in 2015, my health unraveled on every level. I ended up having to move back home in upstate New York with my mom, and she encouraged me to go see a local Lyme specialist.

At the first appointment, the nurse practitioner asked me a really amazing question that I love to ask everyone now, she said, how are you going to get through this?

Do you have a passion? She said that she found that patients at their clinic who had a purpose tended to have better outcomes. So being a filmmaker, being thrown into the middle of this through my own illness, the illness of my mom, I declared that I would make a documentary about Lyme, even though it seemed very unlikely given the state I was in.

It was a total mess. I could barely read and couldn't even hold a camera on my hands. Her so badly. but she looked really excited and she said, we have another patient here who's your age and he's a filmmaker also with Lyme.

Do you want me to connect the two of you so I wrote a note and she handed it to Winslow Crane-Murdoch my co-director of The Quiet Epidemic. The very next day at his appointment.

So it was kind of kismet. It was like the universe was meant for you two to be together. Yeah, because here you are in a in a doctor's office for Lyme disease and connecting you with another filmmaker.

Right. To do this. It was like, literally like the universe said, hey, you two guys need to be together to be making a film, right? So when did you actually start thinking about this, about Lyme advocacy?

Like, why did you decide to make this? You were sick. Like it was an obvious you would be making a film and a documentary on the subject? Yeah, I think for me, I was just so outraged by what I had gone through, what I was going through, I should say, and what my mom had had gone through. And I think a lot of it actually, it's funny, I

haven't really seen it or stated it in this way before, but I think in part I was driven by guilt over not understanding my mom's situation sooner.

And funnily enough, or it's not funny at all. It's awful. Ironically, I was sick myself, but I didn't know what was going on. So my mom kept telling me about there's this controversy and you know, the insurance won't cover it and the test doesn't work, and you have to get the special test.

And I was just like, what is she talking about? I couldn't even comprehend what she was sharing with me.

Personal Lyme Journey and Making the Film

And so I think suddenly when I was thrown into the middle of it through my own diagnosis, started to speak with various advocates and experts like yourself, doc, thank you for being in our film.

suddenly I realized, oh, there's a story that is hard to tell, but that it's. And because it's difficult to tell, people aren't believing it. And so I wondered, and so did Winslow, if we could tell this story in such a way that would make it believable so that nobody, like my mom would be sick and have her own children, not support or believe her, or that me, myself, someone in that situation wouldn't go 10, 15 years without piecing together that their illness is related to related to tick bites.

So it was we we saw this situation, we were thrown into the middle of it, and we wanted to make sure or try to make sure that fewer people had to go through what we went through to find answers and to get better.

So no. And and that's beautiful. Kind of almost like you're paying it forward, right? Like, yeah. 100%. Yeah. Yeah. Like we found out like we got we found out how many people never get that diagnosis.

Right. And and so and we've actually seen people, you know, at screenings piecing together. Oh my goodness. My daughter who was bitten by ticks on Shelter Island ten years ago.

She hadn't been the same since. And we've seen it paying it forward since then. We can talk more about that later. But but it's happening. So but yeah, I, it's really meaningful for me to be here with you right now, doc, because you helping my mom is what led me to be able to get my own diagnosis and make this film.

So it's amazing how we're all connected in this really beautiful and bittersweet way. Right? It's it's a hard situation, but we're making the most of it.

Right. So you're sick. You're making a Lyme documentary. Not an easy thing to do. Winslow is sick making a Lyme documentary, right? I mean, this is this is incredible.

I mean, it's a tour to, for us alone just thinking about what you did. So with all the effort you put in. And I know what it took because you were you were following.

You were following Julia to India, you followed me to to Amsterdam. When I was talking, I watched, you know, how much you were doing your ultimate dreams and goals.

What did you hope to accomplish? Because it was so much time and effort you put into this. And of course, it's a wonderful documentary. I saw different cuts of it, of course, along the way, because you were showing me in the final result was just wonderful.

What was your final goal? What did you hope to accomplish, and did you know about the Lyme politics? You were discussing this earlier with the ILADS versus IDSA because this is part of the film, and you kind of linked it and tell tell everyone a little bit about this.

Yeah. So I did know about the politics early on because of my mom. So she was kind of filling me in. I didn't understand to what extent it was controversial and political, but I to be honest, I was very nervous to make this film.

I was afraid I was, I was pretty afraid to venture into this territory. And I still am a little nervous at times because, there has been retaliation against doctors and advocates and journalists and people who are, you know, shining a light on what's going on with Lyme disease.

So I was aware, but I just felt like I didn't have a choice. So, you know, I just went for it. And I mean, one of the main things that we wanted to achieve was reaching the general public.

We didn't want to make a film that just kind of stuck within the echo chamber of the Lyme community that already knows this history. We wanted to make a good document, not just a good documentary about Lyme, but a good documentary that would reach beyond the community and into the general public.

And fortunately for us, we were connected with this amazing film team that are legends, kind of Baker headed US films. They've been they've been making films for longer than Winslow.

And I had even been alive. And so they came into the fold a few years in and yeah, I mean, we filmed 700 hours of footage over the course of six years, and we gravitated towards these stories that showed the struggle, but also demonstrated hope and that our main subjects don't give up.

And I think that that is what we really wanted to show. We wanted to show that Lyme disease is a really hard situation. And we did not want to sugarcoat that because we wanted the general public to understand how serious and Life-Threatening this is.

But we also wanted to show people who answered the call, and they they didn't just roll over and just say, you know, woe is me. They they took this situation and they transformed it in a way that would benefit not just themselves, but others.

And I think that's kind of in the ether of the entire creation of the film. That's mine. Winslow's story too. That's Julia's story. You know, she's she's advocating for others.

She's in a pre-med program now, as you know, doc, which is so cool. And of course, Dr. Neil Spector, he changed the entire focus of his research to Lyme disease after getting sick.

So we wanted to show relatable characters that were relatable humans, not just look at these sick, suffering Lyme patients, right? So that people who are well, could identify with them and not need the personal Lyme connection.

And so that's happening, which is great. We also wanted to make a film that was rooted in the science so that we could reach, the medical community and even skeptics.

And I'm happy to say that that's also happening. So there was a, review and variety by this renowned film critic named Owen Gleiberman, and he had written a review of Under Our Skin in 2008, which was a great film for that time.

It was great, but so much has changed over the past, you know, 15, 16 years. And he basically said that he had written a hit piece of Under Our Skin in 2008 saying Chronic Lyme doesn't exist.

And then 15 years later wrote a review of The Quiet epidemic and said I was wrong. This film makes the case that chronic Lyme does exist. Which is which is, by the way, a big deal when you're getting a journalist to go 180 degrees in the other direction.

You know, I didn't realize, you know, we hear about the courage of the Lyme patients to keep going, right? Like Julianne and Neal, of course. And, you know, we we hear about the courage of some Lyme doctors, right?

Because you have to fight against the odds. I didn't realize it required courage on your part, like you, that you would actually take a hit as a journalist telling a story this way.

Can you talk a little bit, a little bit more about that? Like what kind of pressure did you have, like in putting this film out and what were the obstacles that you faced with this?

I'm so glad that you asked that question. Well, okay. So, so many obstacles. I mean, I was I was afraid, I was just nervous, you know, I had some weird things happening with my computer at one point, and it seemed like my computer may have been, sort of like, hijacked.

And maybe somebody was watching on my computer. We received some emails from the other side of this debate, basically saying our legal team is going to be very closely watching your film.

Lyme Politics, Science, and Documentary Goals

Each time that something like that happened, I just had to come back to this, like fierce knowing in my heart that, like, I know that we are on the right side of this and, you know, and it's so much bigger than me and my comfort zone and and doc, you're really inspiring, too.

I saw the way that you take care of yourself and the way that you, you know, put others, you prioritize the, the care and the compassion of others. And so I just led with that, and I keep leading with that.

Right. But something that was really challenging for us was when it came time to release the film online. And we because of our teammate Chris Hegedus, who is one of the governors of the documentary branch of the Academy.

Right. The Academy Awards that we all know. I mean, she's in this field in such a big way, and she's friends with and knows all of the major platforms.

I can't say the names, but all of the platforms that we all know. She had private conversations, personal conversations with many of the heads of those platforms, and they were all super supportive of the quiet epidemic. This is an amazing film. It's so important.

But this is a liability to take on these powers where they, as these major organizations, were afraid to tell this story, which then it's just like, oh yeah, of course, that's why this story hasn't really been told yet, right?

We kept wondering, this is so big, why hasn't this blown up yet? And it's because people are afraid to be the messenger of this story, right? Speaking truth.

Speaking truth to power is is never an easy thing. It takes a lot of courage. I think the surprising thing, because you and I know each other well and I you know, of course, greatly.

I know what it took for you to do this. I was watching you out on couches, exhausted, traveling all over the U. S. and the world to be able to do this film.

I don't think people realize, by the way, how much, how much work it is to do a two hour film. That was 700 hours of filming, right? I mean, that's a lot of filming to be able to do this.

So what? So your courage, by the way, I want to congratulate you because speaking truth to power is never easy. But you understood how important it was to tell the stories and to get the message out.

And, you know, and from my background, it's like you get a lot of karmic bonus points for that one. Boy, that's not only building character, right? I mean, because obviously all of us who've been in this field have had to speak truth to power of what we know to be true, right?

Yeah. So so I question unexpected results. You go into this, you're putting so many hours and time in this, and the film explained a little bit, not only unexpected results, but how is the film a bit different? You mentioned Under Our Skin there was a new one, The Monster Inside Me.

How was the film different? How does it vary and what were you not expecting to come out of this whole process? Yeah, well, I think naturally the film being, you know, coming out 15 years after Under Our Skin makes it very different because the research has progressed so much since then.

So in the film we have, you know, Dr. Monica Embers at Tulane speaking about her work. We have Dr. Ying Jang who is at Johns Hopkins, we have Dr. Brian Fallon at Columbia, and we film so many other scientists who didn't even make it into the film, and we will be rolling out extra footage on social media in the coming months, which I'm excited about.

But so the science that's huge. And, you know, we have journalists like Marybeth Phifer and Pamela Weintraub. I believe she wasn't under our skin, but Marybeth Phifer, like, you know, we have these new voices, this new energy that's showing that this problem is not going away.

There are new people getting into this field every single day, whether they're doctors, scientists, journalist, filmmakers. I mean, it's just endless.

And so I think it was really important to show that it's not this old problem. People associate Lyme disease with the 90s because they were hearing more about it on the mainstream media in the 90s, which we also show in the film, may have had to do with the fact that a vaccine was coming out at that time.

but yeah, so we needed that. We needed an update. And I think it's different from the monster inside me. And that, I mean, most obviously, because Winslow and I are patients, and we decided not to put ourselves in the film.

So the Monster inside me is a very beautiful, personal exploration of the journey of this couple moving through through chronic Lyme together. And, Winslow and I, people did encourage us to put ourselves in it over and over and over again.

But there were so many much more credible and reputable voices to speak about. This yourself included, doc and, I mean, it was such a challenge to edit this film down to an hour and 40 minutes.

It was painstaking. It took us almost two years in the edit to get this to a place where it felt solid and, it was fact checked by a very high powered legal team, which, which has held up and, Yeah.

So so we just wanted to sort of make this like, we wanted to just lay it all out, you know, and we could only scratched the surface, even still. But we wanted to show the history of the controversy.

How did we get here? And now that, you know, after watching the film, people realize how we got here now and into the film's impact campaign. We're talking about where do we go from here, too, because it's a it's a tough fight, as you know.

No. And, you know, it's even tough keeping up. I mean, you had 700 hours of film, but people like Monica Embers, I mean, just a couple of months ago. Right. I've been doing this, some combination therapy now.

I've published eight articles in roughly 8 or 9 years. And just a few months ago, she came out in the mouse model that rifampin and daptone is completely eliminating the infection.

Right. So even making a documentary like this with people like this, I mean, the science is constantly changing. So, you might even consider doing an update, you said on this or kind of releasing some of this other footage at some point.

Well, this is the thing. So people tell us all the time, you have to make this film about Lyme and this film about Lyme. I will never make another feature film about Lyme disease, not because I don't care, but because there are so many other stories to tell.

And I think this was, you know, almost it's been almost a decade of my life dedicated to this. And, and I'm focused

on, you know, the aftermath of the film and the impact campaign.

But we do have social media as this amazing tool. Right? So, so the film kind of catches us up to, you know, 2019, let's say 2020, which is when we stopped filming Covid, put an end to our filming.

and now through social media, people can kind of tune in and over the next, you know, in the coming months and possibly years, funding permitted, we'll be able to bring people on to our social media and have Instagram live with them and interview them in real time.

We don't need to drag our gear all over the place and, you know, make it all fancy and we've already made our case. You know, we we we made our case with the film and now we can come in through social media and hopefully on our website as well with, with the updates on, on the science in the state of the treatments, in the diagnostics. No, that's that's great. Thank you.

How do people contact you, by the way, if they want to learn more about the film, they want to help with this impact. We're going to talk a little bit in a second about, this kind of impact that you're doing.

I didn't realize you were having a major impact campaign that was going, I don't think most films do this after it's done. It's out to help people a little bit about how they can contact you.

How can they help with this impact campaign? Great question. so first of all, my email address is Lindsay at the quiet epidemic.com. There's also a general email.

It's contact at the quiet epidemic.com. And our website, there's there's a newsletter sign up and we are also on Facebook and Instagram. So the impact campaign this is this is it's not normal.

And I will say that before I even met Winslow, I knew that I wanted to make a documentary about Lyme, and I wanted it to be an impact film. The first person I ever met with was an impact producer, who is now one of our impact producers.

Eight years later, I met her. I said, I want to make a film that makes a difference. And so we had this in mind from the very beginning that we didn't want to just make a film, put it up online and just kind of, you know, move on with our lives.

We understood that, especially with an indie film especially and meaning and independently film, produced and funded film. And I would like to acknowledge our donors at some point, too.

That's very important. This film was funded by very generous donors, 100% funded by donations. but we didn't want to just throw it up online and move on.

We need to push it out into the world and ensure that people actually see it and not just see it, but also take action. And so there are a few components of the campaign that have been ongoing over the past, you know, almost a year now.

One of them is the community screening tour. So anybody can sign up to host a screening through our website. We have had, I think, around 50 or 60 community screenings at this point, hosted around the country and also in Canada.

We have screening requests from other countries as well. And beyond the screening, they are followed by post screening panel discussions like the one that you attended in Glens Falls.

Echoes of by the way, I'm Action Network. So it's really amazing to see people in their community bringing the film to universities, to their their children's school, to local libraries, to community centers, even in their homes.

And then they're able to have conversations at the local level of how are we keeping our community safe, and who

are the local resources that we can refer people to if they're looking for help.

Right. So there's the community screening tour side of things that's ongoing. and that has included some medical school screenings, which we can talk about later.

one of whom, one of whom you and I know very well. yes. And another family member who's going to med school and another family member who's got right this family, this whole family's been.

Affected by family. they're our main subjects in the film. I'll just. Okay. Brief anecdote here. They brought the film to NYU Medical School because one of the one of Julia's brothers is studying there.

And the reaction from the audience, which was mostly doctors and, you know, faculty and medical students, was one of shock and surprise and in some cases, outrage over having not learned this information in medical school or at all.

Why haven't we been told this, these, that this is what they were saying? If we had learned this sooner, it would have changed our lives. So just to be clear, I want to make sure everyone out there who's listening to this and by the way, I'm in case you're just tuning in, this is again, I'm co-host Dr. Richard Horowitz, and with Lindsay Kee, we're talking about life advocacy and the, The Quiet Epidemic, which is an amazing documentary online.

if you haven't seen it, I would suggest, either scheduling for an impact to get it to your community. or you can out you can still watch it, I'm assuming on Prime or on Apple TV and and Amazon. Yes.

So, the amazing part about that is, James, precisely who I had been training. Right. James would come up to my medical office for years, and he was training with me before as he was in med school.

And he told me ultimately in his fourth year, like they were all surprised, like how much you knew. And you know, what a great diagnostician. And of course, when you're with someone who's been doing this for almost 40 years, it helps.

But I was shocked also to hear that in the med school where James was at NYU, these students, in this day and age, in the middle of a full blown epidemic.

And why the name The Quiet Epidemic? I mean, really, that's the case.

Challenges, Funding, and Impact Campaign

There was outrage by the students that they really didn't know enough about this and realize how bad this was. So that's that's really a surprising I like.

I would have thought myself, even the medical schools at least give a little bit more information, even if they talk about the controversies. Exactly. Yeah.

I mean, just look at the numbers of people impacted. Right? And the fact that Lyme is a cousin of syphilis and they have maybe a page, you know, look for the bullseye rash, run, the two tier Western blot, no discussion of the bans on the blot or how their, their, interpreted, which you did an incredible job of explaining.

Doc and the the quiet epidemic, even people in the Lyme community who thought that they knew it all reach out after watching the film and they say, oh my goodness, I had no idea about the test.

They did not understand just what those bans meant. And so it's amazing that now more people are educated on that and they can advocate for themselves and their loved ones when it comes to, you know, the data that people are given from their their diagnostic test. But.

Right. Yeah, I mean, a, a page, a page and, and an entire medical school education about Lyme and never mind

other tick borne illnesses. That's absurd.

So it's great that it's great that the film is reaching these people and it's at least, you know, encouraging them to ask more questions. You know, we always say that the the film we could not cover it all.

There's no way. But it's the start of a conversation. Right? You know, it almost makes me wonder as you're describing this with this impact, that you're trying to have this impact campaign, whether actually you may want to get a group of Lyme advocates together and see if they can get this in front of other medical schools, because now that you're describing to me what happened with James at NYU, yeah, maybe it actually makes sense to get a group of people with this impact campaign to try and bring it to the medical schools.

100%. That is one of our biggest goal. So we've we've screened it at NYU, Mount Sinai and USC's School of Public Health thus far. And we're in conversation right now with some other medical schools as well.

the good news is that we now have a one hour long cut of the film. So this is a brand new update. An international distribution company reached out to us, and they wanted to bring the film to other countries and, through, broadcast, which means, you know, an hour long cut that would be shown on, on television stations and would be translated into other languages.

So that's happening. The film is now entering other territories around the world, which is very exciting. but that also means that we have this one hour long cut suddenly.

So. So they're looking for a one hour cut for these other countries? yes. So we have a one hour long cut, which now we are able to take to medical schools, they'll be much more likely to screen it because it's shorter and, you know, med school students and faculty are in high demand.

But but we are hopefully returning to Mount Sinai this spring, after the screening that we had there last year, they said, let's keep doing this. Let's do this every year until this problem is solved.

And, yeah. So, so anyone that has, you know, the burning desire to bring this to a medical school, and have a post-screening panel discussion. I mean, I can't name the name of the university, but we are in conversation, right now with the team at a major medical university.

And they said this film would be great at sparking healthy debate amongst doctors and scientists who are on both sides within their medical school. And I love this image and I love this image of the film bringing together these two sides and encouraging a conversation which, you know, may have been happening in their own silos.

Right? And really having that conversation is so important because even after 40 plus years, right, since Alan Stiller discovered this with Willy Bergdorf for we're still dealing with major Lyme, you know, politics.

And, you know, that's why this year I hope to be able to fundraise and do the first randomized, controlled, double blind, placebo controlled trial, multicenter on DAB, some combination therapy, because we're seeing great results.

and, I can't speak about patients directly. I can tell you about my wife Lee, who just has you have had Lyme. You know, I got two years ago, but I got it early, so I never got sick.

But my wife had been sick with it for over 20 years, and she's now over four years in remission without one symptom. after addressing all of the factors on the 16 point message model that's, you know, in my books, how can I get better and why can I get better?

But the dab, some combination therapy at the higher dose put her in remission. So, you know, there is hope and you need the dialog, right? Because a lot of the patients, a lot of the doctors are just not aware, are you able to say, by the way, the, the funders and the people who supported it?

I mean, I can say it, I want to yeah. Thank you. So because because Mount Sinai also where you mentioned the

Cohen Foundation is actually funding Mount Sinai to open up a line clinic.

So why don't you talk a little bit about them? Yeah, exactly. So yes, the film was funded by people who have a very personal connection to this illness and some who don't.

But they are they're afraid that they might. They're worried about their children and their grandchildren. So our executive producers are Phyllis and Scott Bedford, who are the founders of the Limelight Foundation.

Limelight Foundation gives treatment grants to children who are sick with Lyme. They see a lot of, pediatric line, but also, congenital Lyme disease cases, children who are being born to mothers who are sick and the children are born ill, which is a major issue.

So Phyllis and Scott, they're our champions. None of this would have been possible without them. And they still are there helping fund our impact campaign as well, which is just incredible.

but they also need help doing that. They want more people to come in and help us out. So anyone who you know might feel inspired to join our team and, and actually fund this work, it's, it takes a village.

So, yeah, Phyllis and Scott, the Steven and Alexandra Cohen Foundation, crucial part of this story, not just our film, but the field at large. It's amazing to see the work that they've done and and funding the research.

And Alex Cohen and Ben Nems are this film also would not have happened without them. And the very align Foundation, Lori Woods and Linda Jump are two of our executive producers.

They're funding incredible science as well. Isabelle Rose, she's the founder of Mothers Against Lyme, which is a group focused on congenital Lyme disease.

She's one of our IPS. And Serena Snyder, who is a a person who's personally impacted. She's become a dear friend over the years, and she's also a journalist, so that those are our core funders.

Some of them actually wish to remain anonymous, which is also interesting. They're like, we don't need our names on it, just go change the world. And it's so cool to see that there are people out there who really just support, the arts and understand the importance of independent filmmaking to.

Right, because there are a lot of media organizations out there that have financial ties that, complicate their ability to speak freely about the issues that.

Were there was a very good word. It was a very good word. You chose. Yes. You you were very careful in that they complicate the matters as opposed to obfuscate.

corrupts. Yeah. It complicates it. And and I think it's so important that we, as you know, the in the general public really have a critical mind about where we're getting our information from and who's funding the the outpouring of that information.

And some people would say, oh, well, you were funded by the one community. So but yes, yes, but we had the film fact checked by a legal team that had no connections to Lyme disease whatsoever, and we were just relying on facts.

You know, we really tried to maintain a center in telling the story. We tried not to go too far into the anger or too far into, you know, these like extreme, more extreme accusations, which we could we could have made probably in good faith.

But we tried really hard to just like, you know, hold this center again so that it could reach these and open these skeptical minds. Right. You didn't.

In other words, you didn't want to start with Plum Island and basically basically have a drone, have a drone over Plum Island, this secret bio, you know, research facility.

Right. We want to start the film there, right? No, no, we did not want to start the film there at all, although that is an important conversation. And and I do look forward to hopefully bringing Chris Newby on to our social media at some point this year to talk about her, her book and, and the work of Willy Bergdorf. Her.

But yeah, that wasn't our story to tell. and I think we're we're all just chipping away at the same block here. but the other thing I wanted to note about the impact campaign that's very important is we're taking the film, the Congress, and we have been working for, I guess, about six months now with a congressional impact strategist and producer name, Sonia Bonza, and she has worked on many human rights issues.

So she's not a Lyme advocate coming in. She's a human rights advocate coming in. And she watched the film and she said, I want to be involved in this.

I think that this film could actually move the needle on this issue. And she has helped, she has helped get legislation passed in the past with other films.

And she is now leading the charge to set up a bunch of meetings, this spring. Ideally, if everything goes according to plan, we will be going to Congress and with very clear calls to action, one of which is that we want a congressional hearing on the state of Lyme disease diagnostics and therapeutics.

So in 93, there was a Senate hearing called Lyme Disease A Diagnostic and Treatment Dilemma hosted by Senator Ted Kennedy. I was four years old when that happened.

And look at my health. I'm doing well these days, by the way, thanks to doctors like yourself. Doc, thank you for helping me regain my health. but I shouldn't have gone through.

I mean, there should be a test that works, and there should be a treatment that's offered, right? So it's. I was four years old when that hearing happened, and and the as far as the clinic goes, what's happening in these clinics around the world, people are still following the IDSA guidelines, which are endorsed by the CDC.

They don't know that there are other treatments available. They don't know about the eyelids guidelines. They don't know about the other testing. Right.

So we really want to call for a hearing where we can bring people to the stand who can give testimony and get this on the record, because I and I always say this, even if everything was solved with Lyme disease, tomorrow we have a cure and we have a perfect test tomorrow.

This story is still so important. It is important that we get this situation on the record, so that things like this don't happen again with other people.

And it's stark, right? I mean, the CDC reported this the year before that. It was almost a half a million cases, 476,000 known known cases of Lyme disease, the average, they're saying from prior studies, 2 million post-treatment Lyme disease.

Truthfully, we have no idea because 5% of the US population has chronic fatigue, myalgic encephalomyelitis and fibromyalgia, which means at least 18 million people are walking around with a chronic, fatiguing musculoskeletal, neuropsychiatric illness.

And it may be Lyme, right, not just viral infections. And and you and I both know regarding congressional advocacy, one of my highlights, by the way, I would say in my career is when you and I got in my Tesla with 535 books of my last book, How Can I Get Better, which will fit in the car with your equipment to film?

And both of our luggages and I went, how am I going to fit this in my car? And it was like we went to Congress. You

and I were walking around the Senate giving out the books right?

We were there when Comey, you actually was was testifying about Hillary. I mean, we were there on the day when this whole thing broke, right? Which is in the film.

For those of you who've not watched it, you've got it on the screen in the background that that was the day we were in Congress, kind of trying to raise advocacy while you and I were there.

Yes. It's so important that we keep going to Congress. And this is the thing, right? May is Lyme Disease Awareness Month, which is great. People tend to converge around that month.

We do too, but we need to just this needs to become a year round thing. And I know that everyone has different bandwidths, and it's really not fair to put the entire burden on sick and suffering people.

I think that's part of why, you know, it's been hard to make certain changes in this situation because everyone is just maxed out, right? The doctors are maxed out, the patients, the caregivers are maxed out, the foundations are, you know, just hustling, trying to raise that money for the research and that's why, again, I think galvanizing support from the general public is going to be so important because that's what changed things with HIV Aids.

It was healthy advocates who showed up and they were marching in the streets on behalf of the people who couldn't. And I think that, you know, through this film, we have the ability to we are a megaphone, right, for what's happening.

And behind all these closed doors, while everyone is tirelessly working and trying to, you know, push progress or just stay healthy or take care of their loved ones, like the film is out there speaking for us.

It's it's out there right now speaking for us. People could watch it any day. And all of a sudden, these things that we know and that we sort of take for granted, they have their own moment of realizing, oh my goodness, I had no idea this was going on.

Right. You know, and you bring up and you bring up an important point from the patient standpoint, because a lot of times with family members, they really don't understand what the patient is going through.

And by producing a film like The Quiet Epidemic, you give people a viewpoint into people's lives who suffered with this, like especially with with Neil and Julia specifically.

But others. And you show them what this is and I think, maybe speak about this a bit. A lot of people have walked out of their, their family members specifically going, oh my God, I had no idea.

Yes, that's I'm glad that you mentioned that. I'm going to move my camera a little bit. I'm like getting blasted by the sun, or at least so it's even.

Okay. There we go. just a little powerful anecdote here. On that note, this wasn't this was a surprise impact of the film. That was one of the questions that we had talked about.

It's like. We had an idea of certain impacts. And we have, yeah, these huge goals. If we want to go to Congress, we want a hearing. We want the doctors watching it.

We want, you know, we want insurance coverage. We want, you know, the elides guidelines, to be acknowledged alongside the IDSA guidelines. Right. All of that. And more.

And yet that real human impact like you just described, doc, the family members watching this and realizing that has been so profound, I'm going to try really hard not to cry while telling the story.

I cry almost every time, even though I try not to. At our world premiere at the Hot Docs International Film Festival in

Toronto, we were there, Julia was there, and Rico was there.

Community Screenings, Medical Schools, and Congress

We were on stage, our team, and it was the first Q&A we ever had. We had no idea how people were going to respond to the film. Right. We I mean, and the amazing thing about film festivals is that you have general audiences.

It's not just a bunch of people with Lyme disease. It's like a bunch of people who just like documentary films. This hand goes up and oh, it was just it's nerve wracking, you know, it's been seven years of your life on something, and it's so deeply personal.

And it's just like, you want to make everyone happy and you can't. And this woman just burst into tears and she said, thank you. This is the first time in, 20 years that I've seen my story told.

And then she just started sobbing, and and she couldn't even she couldn't even say anything more than that. But it was just, I think that made it very real for the rest of the audience, who may have not been impacted by Lyme, or all of a sudden they're like, wait a minute, this person who's sitting right there who like otherwise just looks like a, you know, a woman in her, maybe her 40s or what.

And, and but what was even more profound was after the screening, we were in the lobby and she was there with her two parents, and they came up to me and her parents said, we need to thank you, because this is the first time in 20 years that we've believed her.

Wow, wow. It took your film for the parents to turn to the daughter and go, we finally believe you, that you weren't making this up. It just wasn't in your head like it was some crazy.

Oh, that is that is profound. That's profound. That must. That really touched your heart, right? Like, wow, I made a difference in the world. And by the way, even one person like that, when you I mean, it's like it all makes it worth it. Right?

And and what's amazing is that we've seen that happen over and over and over again. And, you know, we've probably in person attended, I don't know, at least 50 screenings of the film in person at this point. And, you know, people come up and talk to us afterwards, but they also send messages through social media.

And I've heard that from so many people that watching the film brought their family back together. So it's helping people mend their relationships and I know that we all are really longing for a cure and a test that works.

And yeah, all the things that I mentioned before, insurance coverage and on and on and on. But the power of belief, of having somebody believe you and be there for you and care for you, I mean, that's the beauty of the bruises you family that shines through in the film.

You know that when you have people who rally around you, you have a much better chance of getting better, right? And and most people, by the way, don't have fathers like Enrico.

I mean, I mean, I mean, the man is a force of nature. I've been over there for Christmas. I mean. There's a force of nature, right? It's a whole nother story to go with that.

But when when you see the way parents can rally, I mean, also great point around children. It's heartening, right, because some of us have had dysfunctional families growing up.

You get to see, like, even if people have not always gotten, you know, together or they had issues the way they rallied around it, it was it was such a beautiful thing to see.

And still artistically. Yes, it shows us what's possible. It raises the bar for everybody. You know, how to show up in

a challenging situation. I think some people would rather just plug their ears and look the other way and pretend it's not happening, but that doesn't make it go away.

And Lyme disease is actually an opportunity to really deepen your relationships. It shows you, who your real friends are, but it also provides the an opportunity for forgiveness.

You know, I had some friends who did not show up for me. And years later, we had conversations about that. And I could understand why it was scary for them to see someone their age in our 20s at the time, you know, basically, like, fall into multiple sclerosis and dementia over the course of, you know, a few months.

I spiraled quickly at the end and, so. by the way, people should know people should know that during the seven years that you made this film, it's not like you were.

Well, the entire time doing this, I know. So I mean, again, talking about the courage, the stamina, the goal of I have to help the world with this, right?

Just one person's motivation. I mean, you and Lindsay, you know, together, with Winslow putting this, you know, on film for people to see, think about how many lives now it's touched.

I mean, I'm sure were there other unexpected things? You you know, I know when you start making a film and you're putting this much time and effort you have, maybe certain expectations are the ones that were met and ones that you're actually really.

I think the family one was someone you were surprised at. Were there any others? yeah. I think the other one of the other surprises being impacts of the film has been, I have scientists reaching out to me.

I'm like, I'm a filmmaker, right? But like, hi, like, we have this idea, like, can you like, we want to like we didn't understand. Like they watched the film and they're like, oh my God, this they need help.

This community needs help. And so it's been really cool. Well, I have some teams reaching out to me, like from around the world, even just saying, like, like how do we get involved?

Like how do we get like saliva samples or bloods that I'm like, okay, you need to talk to the Lyme Foundation, know about this. And, and I can connect them with the right people.

But I think that's been pretty cool to see, because this is the cool thing about documentary is like, is people just like documentaries, people from all walks of life.

And so you have all sorts of people who are watching the film who might watch it and say, oh, I can get involved in this with whatever their niche is, whatever their, you know, line of work is or whatnot.

So that's been pretty exciting. I'm like having zoom calls with like teams of scientists and stuff. It's so weird. Oh, you know, I didn't know this is the first time I'm hearing this from you.

I mean, I speak from time to time. I didn't realize that that was an outcome. That's amazing. I you've actually got another scientist involved to want to do this after seeing them.

Yeah yeah yeah, yeah. No, that's that's been really fun. And and also people who are aspiring Lyme doctors now and they didn't realize that, you know, they just people just they, they didn't know.

And just like I didn't know until I was thrown into the middle of this. But but now people can watch the film and they can learn without getting sick themselves.

And that was like, you know, that's the biggest goal because everyone says in one community, you don't know until, you know, meaning like until you're unraveling or someone close to you is unraveling from tick borne illness.

But does it? What if it didn't have to be that way? What if someone just like, watched a film and felt like this, you know, purpose ignited in them and then they, you know, went for it without having to to fall ill, to be called to action.

So, no, I think that's been part of it too. Yeah. And you know, in regarding even regarding the congressional advocacy, you know, because you were there with me in Washington, DC, but, I mean, I served on the first round of the HHS tick borne Disease working group, and we came in about a year late, and they needed to get a report to Congress right within a year.

That was the way Obama had written, you know, the laws with it. And I must have put in 40 hours a week, right, for free for the federal government. And it was basically in service of the American people trying to, you know, give Congress more information and understand the severity of this and what's even a little bit frustrating because, you know, it's over now after six years, is I think the needle may have moved a little bit, like, I think my private conversations, maybe with certain members of the CDC, the NIH, the FDA, the Department of Defense, because they were all involved in this.

Right. I think maybe they believed me after hearing my stories. And let me quote science and doing this, it made a difference. But boy, the politics are still not great even at this point.

Which is why for me, I'm this year going to be, you know, fundraising and hoping to start a multicenter, randomized, controlled, double blind study on that soon because I've now seen enough positive results.

I'm convinced of the results. There's no doubt that I have found, if not a cure, and I don't know what is a cure. I mean, it either could be I'm really knocking fully the bugs, or what's more likely, I've knocked out 99.9% the immune systems handling it.

But for all intents and purposes, people go live their lives for years, like my wife and others now who are in full remission. But it's so interesting because even though I publish article after article on that, so and and here's the protocol and here's how you do it.

I still can't get doctors to do it because they're worried about the side effects of that. So which is, by the way, part of the reason I'm doing this summit is to keep educating people about this, because just like you kind of have the moment, I need to do this to raise awareness.

It's the same thing for me, and it's really step by step. This is a very slow process of changing this particular field where you'd think, considering it's an epidemic proportion across the world, the politics.

I don't think anybody who hasn't realized like what this is, they would never know. The politics are this dysfunctional, that, you know, you had to make a film like this to raise awareness.

And I have to keep publishing articles on that. Right? I mean, this is what it takes. All of us, all of us do our part, right? All of us do our part. And yeah, I think it's like important to to make that clear, doc.

Like like you said like I didn't I didn't aspire to be a Lyme documentary filmmaker. Like, this is not this was not the plan. You know, this is not the plan.

And so it's like, you know, clearly it's an issue when so many people are being called to dedicate, you know, years, decades of their, their life. A lot of it. Yeah.

Unpaid or not, not paid enough. I mean, the sacrifices that me and my team made financially, like personally to make this film, even with all the generous support that we had, is like, it's like altered the course of my life, you know, and and it's but that's how big of an issue this is and that's how important it is.

And so, yeah, we're all making these sacrifices and hearing you talk about your study and, and, you know, needing funding for that just reminds me to to note that, you know, part of what we're going to be, you know, discussing with Congress when we go there is that, yes, we need more research funding for Lyme disease, but we also need that

funding to go to very particular people who have been on the front lines of this, and not the same people who sort of churn out the same findings year after year, that just maintain the status quo, that that benefits their professorships and their careers and their their products.

Right. We need the funding to go to people like yourself who are actually with these chronically ill people and who have a vested interest in getting them better.

And it's it's it seems so obvious. But, you know, the research funding, when it's controlled by the same group that is just self-sustaining year after year after year, it's no wonder that it's been so hard to know.

And and that's why, like, for example, I had a very nice grant from the Bay Area Lyme Foundation years ago to do my precision medicine one and two studies.

the Message Research Foundation, which is a five and one C3, I found it has helped me to publish. But but you're right. I mean, this is really a village that's coming together to do this.

and by the way, when you do go to Congress and do this, you know that my hand is up here to be able to help if, if you need it because I well, I have given both of my books I got and Chris Gibson was in Congress, my first book, which which the New York Times bestseller, Why Can't I Get Better?

that went to every member of Congress through Chris Gibson. And lately you and I started doing it, and, so but I've been doing the same thing. And I think eventually every piece of this, we just chipping away little by little with these documentary, these books, sending letters, it's I think you and I both agree it is going to change.

it's just been slow in the process, but I feel like we're reaching a critical point very soon enough. You can feel it also that we're very close.

Audience Impact and Closing Remarks

I feel that, yeah, I feel it because I think the advocacy has become so powerful and meaning some of the people who are getting involved or they themselves are powerful, they have the power to to shape not just the science, but but legislation.

And like you said, the Cohens are funding this research at Mount Sinai, the center with Dr. Patrina. I'm very excited to see where that leads the the it's too big at this point.

It's it's the cat's out of the bag. And I think that the people who were trying to keep the cat in the bag for decades didn't know that the internet was coming.

They didn't know that social media was coming. They didn't know that millions and millions of dollars through these private foundations that we've mentioned, that that was coming.

And it's all just reaching this boiling point, right now. And, I mean, it's it's it's only time until they're personally impacted to and I and I don't wish this upon anybody.

I would never want to give that impression. But just given how many people are impacted, the people in government should be concerned. The people at the CDC, the NIH, the FDA, they should be concerned.

What happens if their child gets sick? How do they get their child better when the research has been stunted for for 40 years, you know and and thank goodness for a yeah, the the Cohen Foundation and Bay area Lyme and Global Lyme Alliance for pushing the research forward.

But how do we get the CDC to pay attention to that research and actually endorse that research? Well, you know, I will be speaking with Ben Beard from the, Live Lyme Foundation from Holliday Goodrow, who served as co-chair on the last round.

She knows Ben very well. Right. She's in Colorado. And, and I know Ben very well, and he's a really hell of a guy. He's he's a lovely man. and he gets it.

And, you know, from my conversations with him, it's not even just a problem with the CDC. The problem is in part with the politics, with the NIH. There's a whole that's a that's a whole our discussion.

but by the way, we're getting to the end of the interview. We're almost at an hour. So, any last thoughts? We've we've just got like 2 or 3 minutes left.

Tell people again how they can contact you to be able to be part of this impact campaign. Let, let people know. Yeah. So thequietepidemic.com that's the hub for all things.

So you can find our newsletter sign up there. You can find our social media there. Follow us on social media. You can reach out to us via email. I think you know the film is out there.

Just post about the film as much as you can, right? If each of us got every person close to us to watch the film, and then they got every person close to them to watch the film, that's how we create this ripple effect, you know?

And and so it's out there. It's on Amazon Prime, it's on Apple TV, iTunes. Yes. You have to rent it for 3.99, which, you know, it's one of the most important films, I think.

And I'm biased, of course, because I made it. But as a patient, not never mind filmmaker, as a patient, it's one of the most important films that you could watch for you to protect your health and your family's health. So, get involved, reach out, sign up to host a screening.

Please pay attention in the coming months, because as we roll out this congressional push, we will be calling on our followers and our community to send letters to make phone calls.

We'll be providing all of the scripts. We'll be providing pre-written letters. We'll make it as easy as possible for everyone. We just want to flood Congress.

We want to flood Congress, and we yeah, we really need the community. We're a tiny team. We're very small team. So there are powers, power in numbers.

And for better or for worse, a lot of people are impacted and care about this issue. And I do think that I do think that we're getting close now. You're absolutely correct. And and, Lindsay, I want to thank you today for those of you again who've tuned in.

this is Lindsay Keys She is the filmmaker with WINSLOW CRANE-MURDOCH about The Quiet Epidemic. It's a wonderful film. Lindsay followed me for many years, with Julia during this film.

I saw what she went through. And I can tell you, when I went to Glens Falls for the screening, I was even surprised the quality of the film, the final result, because I saw pieces along the way.

It's just a wonderful, just wonderful film. I advise everyone to please see it. So Lindsay, thank you so much for taking the time today. it was great speaking to you.

and, for everyone again, who has joined this particular episode of The DrTalks I am the co-host, Dr. Richard Horowitz, with my other co-host, Myriah Hinchey.

we are doing, this series for you, right? We're doing the Healing Lyme Summit for you, for those of you out here, for the doctors, for the patients, so you can gain the information and the power of knowledge that you need to be able to get better.

So thank you so much for tuning in and we hope to see you soon.