



How to Get Involved With the MoldIQ Study With Dr. Jill Crista

KS

Kendra Seymour

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Hello everyone, and welcome to Your Indoor Air Podcast brought to you by Change the Air Foundation. My name is Kendra Seymour, and today we're going to talk with Dr. Jill Crista, who, along with Dr. Neil Nathan, received one of Change the Air Foundation's research grants in 2023. So now, if you're unfamiliar with the funding we do there, we periodically provide grants to passionate researchers and scientists and medical and indoor air quality professionals whose research focuses on improving the lives of those impacted by poor indoor air quality. And while we recognize that, you know, poor indoor air quality is an underfunded and overlooked and often dismissed health issue, we want to close that gap any way we can. So, while we fund smaller scale research projects, so in this case, it was a \$75,000 research grant, the projects we fund and want to fund are by no means small in terms of the impact we believe they're going to have. So, I wanted to bring Dr Crista on to talk a bit more about her and Dr Nathan's Mold IQ Research Initiative, because they actually need your help. So, if you're experiencing health symptoms that are, or you believe to be, related to mold exposure, you could be part of making history. And so today we want to talk about this research project and how people can get involved. So, thank you so much, Dr Crista, for being here.

JC

Dr. Jill Crista

1:19

Thank you for having me and helping me spread the word about our exciting project here.

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Kendra Seymour

1:24

Yeah, no, this is so great. And I also want to point out, I know if people realize this, like you and Dr Nathan and the other healthcare practitioner involved, you are all donating your time for free, which I think is amazing. It speaks to the fact this truly is a passion project, and it's so needed. And you know, the grant that we provided covers, you know, data management fees and IRB approval fees and all that stuff. So, the work that you guys are doing and the time, I just want to say thank you. And of course, I would be remiss if I didn't say thank you to our donors whose donations help support things like this. So, let's jump right in, though. So, tell us a bit about the goal of this Mold IQ Research Initiative.

JC

Dr. Jill Crista

2:04

Awesome. Thank you. So, there's a lot of confusion about mold related illness because of the paucity or the lack of research on humans. There's a bunch on animals, but not on humans. And there...so the story about mold related illness stops at spores, and mold can make us sick with toxins, with off-gassing and things like that. So, the reason why we have such a limitation of the research is that we can't take something that has already been classified as a carcinogen by the World Health Organization, which is mold mycotoxins...also been classified as a teratogen, which means causes birth defects. We can't recruit for a study where we say, "Okay, we're going to poison you with these known toxic cancer-causing things so that we can figure out how to get you better." We just can't do that. You know, medical ethics, thankfully, is not allowing us to poison people for research. So, we're stuck with trying to do these observational studies and then getting creative with how can we do treatment-based, interventional type studies using people who are already exposed every day, which is remediators. So, this is the first arm of a big vision that we have, which is to first prove that mold and mycotoxins and toxins can cause human health effects, and then prove or validate a questionnaire so that we can track symptoms and use that in the next arm of the study, which is then using different interventions to figure out, how can we get people better faster. How can we prevent some of the long-term health effects that are happening with these illnesses, and not just sit and wait for their body to sort of, you know, do what it's naturally built to do, which is detoxify. But some people, about 25% of the population, has trouble with that. So, we want to figure out, how can we help enhance that and get their health back faster?

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Kendra Seymour

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Yeah, it's so important, and it's something we see. I am so tired of hearing that mold is just an allergy. And so, and that's where I think you talk to...whether it's contractors or doctors or spouses...like that, is that a default, I think, position for some. So, talk to us a little bit more though about why this questionnaire is needed and kind of the gap that it's going to fill in diagnosing mold related illness. Because there's also precedence for this, right? There's a similar questionnaire for IBD. So, talk to us a little bit about that.

JC

Dr. Jill Crista

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Yeah. So basically, what we're doing is we're just expanding this from other questionnaires, validated questionnaires that are used in medicine all of the time. So, in cases where it's maybe harmful to do, or not...you know, it has greater harm to diagnose IBD because you need to schedule a person for a colonoscopy. And some people, they don't...their health isn't even healthy enough to do that because of their disorder. So, what they have done is they validated a questionnaire, the Irritable Bowel Disease questionnaire, taking volunteers, you know, in research, and putting them through all the diagnostics, putting them through the biopsies, the colonoscopies, the endoscopies, and then looking at their symptoms, and then validating that certain symptom clusters and certain scoring can be used to diagnose it, so that it saves having to have patients go in and get all of these high,

you know, intervention, kind of diagnostics. So that's exactly what we're trying to do with mold.

Is that...the problem with mold related illness is that if you did the math pro...problem of how many different mold spores can live in a water damaged building, how many bacteria can live in a water damaged building, how many toxins, endotoxins, microbial VOCs, mycotoxins, can be emitted from those...now let's do the math problem. So, we're talking when we're talking about mold related illness, the total number of conditions we're talking about is over 250 different ways that this thing can show up. That creates enormous diagnostic complexity. And so, what we're trying to do is take the limitations of the testing that we have and this broad scope of the ways that this mold related illness can show up, and find a way to quantify and identify when it is mold and when it isn't.

So, we're asking volunteers who have any kind of mold testing for your body, for your home, to please submit your data. This is all volunteer. We're not covering anyone's lab tests. We're not covering anyone's home inspection, anything like that. So, we're just pleading for volunteers to please help us out and move the needle here on how...helping us identify mold related illness when it's there, and using a questionnaire that I developed over the last 15 years of my practice, and getting the scoring system right. And, you know, I was testing patients that were coming with other disorders and figuring out, you know, what is the scoring system that we can use. And so, if people would help us with that, we can then validate this questionnaire, and it will help identify mold related illness for people who can't, either can't afford the testing, or there are really bad detoxifiers. So maybe the urine testing isn't a good match, or maybe they have immune deficiencies, so the antibody testing isn't a good match. So, we're trying to find a way to both identify mold and then help people out using these, you know, these questionnaires that we use in medicine all the time.

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Kendra Seymour

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Yeah, and we're, we'll talk a little bit more about how people can become involved and what that looks like. And I, I love, first of all that this is something, a questionnaire that it can be accessible then to any doctor, right? And it's not...the cost of healing your body and healing your home is exponential, and I think because it is so complex, that it could move the needle in really helping to catch people who perhaps are falling through the cracks. But I want to talk about something. You kept saying "validated". And this is something that we...when we awarded the grant, we thought was really important...is you guys are going through the Institutional Review Board or IRB approval process. Tell people why that matters. This is not just like some random questionnaire you came up with, and this is my opinion. Like, no, this is based in science, and it's...tell us about that process and why that's so important when it comes to research.

JC

Dr. Jill Crista

8:40

Yeah, so you can have any kind of idea about research, but then, if it's not going through scientists, it's sort of like having a peer review on an article. You know, that's the difference

between an op-ed piece and something that has scientific teeth. And so, an IRB approved study means that there is a review board of scientists that have certain criteria that they have to meet in order to be called an IRB or an Institutional Review Board. So, we have a board overseeing this entire process. We had to submit our study design, our goals, and the whole deal to them. They had feedback, so it's a back-and-forth process, just like writing a peer reviewed article. And the whole goal with that is that it's going to improve our outcomes. It's going to...they did improve our study with all of the back and forth. You know, that's what's wonderful about having, you know, people that see lots and lots and lots of different studies. They can already identify where the pitfalls are that you didn't even know that you were forgetting. So, they've refined our process, they've refined our study design, and they're overseeing the entire thing. We submit every once in a while, you know, what we're...where we are in our process, and then in the end, they will be the ones that do the stamp of approval of, you know, "they followed the study design. They followed all the rules," so to speak. And that the information that is coming out of the study is valid and scientifically reliable,

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Kendra Seymour

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Yeah, and that's so important. Yeah, I mean, we want this to go mainstream, right? We want, we want every doctor you know to be aware of this and understand the impact that mold can have on someone's health. Now, just quickly, because I think this is an important part, tell us about the data analysis plans, because I want to clear up confusion. You know, Change the Air Foundation...we award the grant. Other than that, we stay out of it. You know, we'll provide periodic updates. You guys are collecting the research, but you're not doing the data analysis yourself, right? You're going to remove that bias. So, what does that look like? Who does that?

JC

Dr. Jill Crista

10:48

Yeah, so right now, we don't have a data analysis yet because we need more submissions.

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Kendra Seymour

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Yeah, that's where you guys come in! All our listeners! Yeah.

JC

Dr. Jill Crista

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Yeah, so once we hit our critical mass of our qualifying submissions, then this goes to people who do data analysis, who can look at the numbers. And our first question, which I'm really excited to answer is, is the questionnaire identifying mold when it's there, and not identifying mold when it's not there? So, we the...what we're needing all the volunteers, is to get the data of people who are sick. And then there's the next step, is that we get healthy controls they call it...so healthy people who don't have water damage, building exposure...get their labs, and then we send it to scientists that do data analysis. And there are certain scientists that specialize in questionnaire-based data analysis. So there...what they will be doing is trying to answer that question..."Is this questionnaire valid?" And if it's

not, how do we refine it based on the analysis to either shorten it or do better with the scoring? Maybe we do weighted averages of the symptom, instead of "Do you have it? Yes or no?" Maybe we do a scale, but we're trying to keep it as easy as possible on the mold sick person, because mold brain is real.

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Kendra Seymour

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And we know you're busy, and stressed, and there's a lot going on. So, let's pivot then. Let's talk about this ideal candidate, who they are. Because you do need a specific kind of person, right, in their journey. And then what the process is like.

JC

Dr. Jill Crista

12:27

Yeah, so we've gotten a few people saying, "Oh, I've been at this a long time. Do you want to know my whole treatment that worked?" and we're not there yet. We do want that information later, but the first step right now is we're trying to catch the person that's in kind of the initial stages of their awareness that this could be mold, and they are just taking their lab tests. Whatever their doctor has decided or determined is the best way to diagnose it. We are totally agnostic about how your doctor is deciding to check this. We're accepting any kind of testing that your doctor has decided. That's also how we can find out later, what are the things that are better at catching certain types of mold related illness versus other types? So that's a that's a next kind of data mine that we can do.

So, we're looking for people that are like, "Oh my gosh, our family's sick. We just saw our doctor. They recommended a, you know, a blood test or a urine test." And filling out the questionnaire. The ideal picture is, you fill out the questionnaire on the day you collect your sample. We have a little wiggle room with our Institutional Review Board that has said people can probably remember how icky they felt a month ago. So, we have a month window if you are just hearing about this now, and you're like, "Oh, darn, we didn't..." you know. You can submit any lab tests that you did if you can fill it out within, fill out the questionnaire within the month. So, we were able to expand that, which was very nice. And they're saying, you know, people are going to...things don't change that fast. And, you know, memories don't change that fast, so to speak. So, we will take that...any kind of, you know, around a month before, after you took your labs.

Please go to the MoldIQ.org...that's the website that is collecting the data...and submit your information. Tell us your symptoms, and then you could submit your lab testing, any building testing that you have. We have a set of questions that are really important for us to start to again determine, is this, is this an important factor or non-important factor? Things like, were you taking binders or not when you took your urine sample? Those are things that help us refine the testing, for people who do want to get the testing. So, that's the ideal person. It can be...we are not accepting children's lab results at this stage because the questionnaire that I developed was really to catch adult mold related illness, which is harder to see. Kids actually get sick, you know, so they're a little faster to catch. And the problem in medicine is that we don't realize it's mold. We call it asthma, or we call it

something else, and it's from a water damage building. But with adults, you know, we're a little more run down. We have more things going on.

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Kendra Seymour

15:09

You're a tired parent. Yeah.

JC

Dr. Jill Crista

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Exactly, it's a little harder. We're really good at suppressing things, you know, using caffeine to get going and, you know, gummies or whatever, to get sleep so we can cover things up, you know. So, we wanted to make sure to be able to catch the adults. So, we do have a limitation of, you need to be 18 years or older in order to submit for the lab, or, you know, your data. And then just sometime in that one-month window that you've taken your labs, please submit your labs and your symptoms, and then you will get a printable PDF that you can share with your medical team once you're done. Yeah, so, and if you are like, yeah, and I remember being this sick where I would have only been able to get through the category one questions, and then need to rest, because the visual impact for mold is so, so real. So, if you are that person, we've built in ways, because we've all been there...to save and continue later. So, if you are a fatigued person, you're like, "I...I'm overwhelmed, even looking at this first set of questions", we totally get it, because we see you all the time. So, we built it in for that very thing. We built in "Save and continue later." You'll get an email with a link that gives you time to then go back and finish whenever you'd like to.

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Kendra Seymour

16:33

Yeah, I...this is, this is so important, right? So, this is something that's voluntary to participate. We want people early on in the journey. You aren't going to get reimbursed for your labs, but this is so important. And you know, something I love about this community is that they've really...they rally together and they support. So, if you're listening, and I know you're tired, and just one more thing, please, please consider doing this. Imagine the difference it would have made in your journey, in your story if you had gotten that diagnosis sooner. I know most of us listening can empathize and relate to that feeling, and if I had been a candidate, I would do it in a heartbeat, because this doesn't change unless we come together to make it change. So, I...this is so important. So, tell us the website one more time. I'll link to it in the show notes for people listening. But what is that again?

JC

Dr. Jill Crista

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MoldIQ.org. The mold illness questionnaire.

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Kendra Seymour

17:26

Yeah, and you have some FAQs on there if people have more questions. But it's all in one spot, and it takes you through the process. And we at the Foundation, promise to keep you

updated as, you know, this research progresses. Is there anything else to share, Dr Crista, before we wrap it up?

JC

Dr. Jill Crista

17:43

Not that I can think of. I'm just so grateful to everyone who has submitted their data. We have about 500 qualifying submissions so far, which is amazing for a completely voluntary thing. So, my deepest gratitude to everyone who has submitted their data so far. We need 500 more qualifying before we can start data crunching. So, please spread the word, but also, thank you. Thank you if you've already done it,

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Kendra Seymour

18:09

Yeah, and please, you know, if you're thinking, "Well someone else will be doing it", please...please consider it yourself if you qualify. We're so appreciative of your time today, Dr. Crista. And for everyone listening who has donated to support this, or who wants more information about the work that we do or the research that we fund, really the best way to get that is head on over to ChangeTheAirFoundation.org, and sign up for our newsletter, and you'll get once a week email. I keep them short, I keep them sweet, and I always try to provide those actionable, helpful tips and free downloads that can help you and your family be healthy and live in a healthier home. So, thank you everyone for listening, and we'll see you next time. Thanks so much.