

Mold and MS: The Lowenstein Family's Story

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Lauren Lowenstein

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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 I'm joined by Lauren Lowenstein, a remarkable advocate for mold and biotoxin awareness. And you may have seen her featured in Newsweek or followed her on Instagram, where she shares her family's journey with mold exposure and biotoxins, and really works tirelessly to raise awareness for others facing similar challenges. Now, I think what makes Lauren's story so shocking and inspiring is really her experience as a young mom, she went from being, I would say, you know, deeply invested in health and fitness, to kind of finding herself on the path to being diagnosed with MS in her 30s. The root cause of her and her family's degrading health was, you guessed it, water damage and the biotoxins that come along with that. So, this episode, I think is really eye-opening. Poor indoor air quality and unhealthy homes really can affect anyone. So, Lauren, thank you so much for being here.

LL

Lauren Lowenstein

1:29

Thank you for having me. Kendra, I'm very excited to have this opportunity to just speak with you and bring even more awareness and attention to, you know, a concern that's affecting millions—and many who don't even have it on their radar.

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Kendra Seymour

1:47

Yeah, I think that's what is so shocking. It is not something that we're thinking about; it's often not something we see, so it's just so often overlooked. So, I cannot wait to jump into your story, but before we do, I do need to take a moment to say thank you to two of our amazing sponsors. Now it is their generosity, along with all of our wonderful donors, that help, you know, us continue to provide free resources, and fund important research, and

advocate for better laws around mold, water damage, and remediation. So, a heartfelt thank you today to Green Home Solutions of Colorado and MV Restoration in Colorado for their unwavering support. You know, we deeply appreciate these companies and their commitment to healthy indoor air. And if you want to learn more about them, or if you're interested in becoming a sponsor yourself, head on over to ChangeTheAirFoundation.org and click on our Corporate Partners tab.

Okay, Lauren, we have, I think, a lot to cover and not a ton of time. So, why don't we start with kind of some of the symptoms you were facing, and kind of that moment when you started to make the connection—maybe between your health and your home?

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Lauren Lowenstein

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Gosh, I feel no matter how many times I do have this conversation, I still never really know where to start. Just because, as you know, it's complex. And so, we moved into a nine-year-old home, and we had thorough inspections, home inspections, and we did not have a mold inspection because it just was not something that was on our radar. Even though, oddly enough, the people that we sold our previous home to left a very toxic mold home and lost everything, and, you know, still, it just wasn't something on our radar. And shortly after moving into this home, I started experiencing things that you would associate with just, you know, I'm a mom of young kids. And I had headaches, and fatigue, and kind of started having some more ADHD-like symptoms. I started having some chronic pain, but being someone who's very into the fitness industry, I associated a lot of my things with, "Maybe I'm training too hard. I lift heavy. I'm a mom" And over time, so, it was a very slow progression over time, in years, but my children were suffering as well. And, you know, it was chronic headaches, and mood changes, depression. I had body hives one year, for an entire year. Insane fatigue. I never would have thought all of those things were related to one root cause; that just wasn't in my mind. I was going from doctor to doctor to doctor.

My children started having insane mood swings for much greater than what would be expected for a child with big emotions, but they also had chronic GI issues, skin problems. So, it wasn't until five years of being in the home that my health really took a drastic turn, and I became almost entirely bedridden and unable to function. And going through...accepting a diagnosis of MS still didn't make sense to me, and a lot of people ask, "Well, what kind of put mold on your radar?" And I still am not entirely sure, but there were some areas in our master shower, that just—I would try to clean the grout, and over time, that grout got harder to clean. And it was a little dark, and I just suggested to my husband, after looking at mold symptoms, and my issues, and my kids, I'm like, "You know, let's maybe, let's test our home for mold." Which was hard on our relationship, because we had...I had been chronically sick for so long, and he, you know, the both of us trying to wrap our heads around MS and kind of accept that, and now we're moving on to something else. But when we did test that, it came back with elevated levels of toxic molds, and everything kind of started to make sense. And that's when we moved forward with having some inspections with IEPs. And one thing led to another, and it just led to a very new journey within this whole thing, because then it was the issue with our home, which was extremely overwhelming to deal with.

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Kendra Seymour

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Yeah, I think what is so hard about this is that with poor indoor air quality, the symptoms sometimes aren't acute, right? It's not always right away; they're slow, and they're cumulative—the effects. And they affect different people in different ways, and so, it's not always straightforward. And you, I think many can relate. It's chalked up to things like, "You're a tired mom. Oh, these things...your kid's just, you know, going through a phase." But then you're talking about things, you know, no one should have chronic hives for a year. That is a symptom of something else, and this insane chronic fatigue. So, I'm curious, when you started to realize that mold was at play? Did you go back to any of the doctors who had tried to diagnose you with MS, and what did they say?

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Lauren Lowenstein

7:16

So, that was tough, because I did go back to doctors, but I also really didn't want to. I didn't want to because I thought, "They're going to think I'm...they're not going to hear me out", or I was too afraid of what they might think. When I did start to mention it to different providers and kind of put it on their radar, it was almost like a completely change of demeanor, of like, "Mold doesn't cause that. Mold? That's not a thing. You would have respiratory distress. You would have, you know, associated with just allergies." Which was something that I never in my whole life really dealt with, until being in this home. And I had a sinus surgery; I had a septoplasty. I had nine different procedures all at once because my sinuses were so bad, my allergies were so bad. With all that said, it was just, I felt constantly gaslit of, "Mold can't do that. Mold can't cause that." And the more that I dove into research, and I uncovered CIRS, Chronic Inflammatory Response Syndrome, which is what I'm very passionate about bringing awareness to—is the genetic component of what can happen when you are susceptible to these biotoxins in your environment. And the further down the rabbit hole I went with that, I felt very, you know, I had that confirmation that I needed of this is what I'm dealing with. I don't really care what these doctors are telling me. And I still, yet, I still never got a provider to order lab work for me and to help diagnose me. That was something that I had to pursue myself, and find a private lab, and run these labs, and find a way to interpret them and what that meant. And then find a CIRS practitioner who was able to help walk me from point A to point B with the proper treatment

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Kendra Seymour

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Yeah, and I think what is true, just, that adds to this layer of complexity, is not only finding the right doctor who understands this and how to address it. It's that, unlike most illnesses, you're also simultaneously trying to heal your home, or move to a home where you can heal. So, we're gonna unpack some of the things. I know you're passionate talking about, the medical and treatment side, but did you guys end up staying in the home? Did you try to fix it? Can you talk a little bit about that?

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Lauren Lowenstein

9:57

Yes, yeah. So, we ended up—it's so complex, as I think so many people know who have been down this road—that we, you know, had to weigh our options of what to do. Do we stay in the home? Do we fix what we know is there so that we can sell the home? Do we, you know, build a new home? And there was just, there were so many things to consider, which was also really hard when you feel like your brain's not functioning. You're trying to make these decisions without brain cells. And so, it really came down to, you know, what was going to set us, set me and my health, and my kids' health up for the best chance of success long-term. And we knew that regardless of it was our home that we stayed and remediated or another home, that we would find that we were still going to encounter problems that we were going to need to fix, even with new builds. You know, the building science is not properly understood. So, the way that HVACs are just being thrown into these homes; and they're oversized and producing excess humidity. And, you know, we knew that even if it was a new build, we would have to come in and make some changes financially.

So, for us, it made the most sense to stay. We knew the problem areas that we were dealing with. We didn't want to do more inspections with another home, and so, we made that choice to stay and remediate—and do a very extensive remediation. And at the time thinking, "How are we going to do this?" No one's prepared for this. And so, we, you know, I know a lot of people listening are in that situation, and so just to share the route that we went, we did a HELOC, a home equity line of credit. We were able to do that, and help us pay for remediation and build, you know, build back, because that's a whole other aspect of things you have to remediate. And we took it a step above just because we want this to hopefully be our forever home, and make it a safe home, and make sure that we got everything as to our, you know, best of our ability, and then build back. So, we've been in a couple of rentals because that's not been a smooth process; as we know, you know, there's no sterile environment. And so, we will be moving back into our home at the beginning of next year in 2025. So, we're looking forward to it. It was...there's been some PTSD with that home making us sick, and where I'm at now and how far I've come, I'm excited to say that I'm actually feeling hopeful and excited about it, and less fearful about it.

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Kendra Seymour

12:58

Yeah, there. There is just so much there I'd like to unpack. Because I think sometimes when you're going through this, people just want to be told, "Tell me what the next step is. What's the right next step?" And what's really hard for people to hear is that there is no perfect next step, right? And it isn't about, you know, there are some, if you go online, "You have to move. You can't stay." And some will say, "Well, I'm staying here. I'm going to fix your home." And I think the message here is powerful—that your situation is unique, and there's no perfect home. So you have to decide, "Am I going to stay and fight for this home?" Which case, you have to think about, "Do I have access to the right IEPs, the ones who are really going to help me go top to bottom through the house and figure out, you know, where my problem areas are, potential problem areas are? Do I have access to the right remediation companies who can fix this, or who can implement, you know, what I like to say is safe and

effective remediation? Do I have the emotional and mental bandwidth to go through this, right? Do we have the money?" And then, you touched on this too, because I've been through all sides of this.

There is PTSD, and I've talked with people, and, you know, one of the conclusions they've had to come to is they're like, "No matter what I do to this house, I don't know if I'll ever feel safe." But then, on the flip side, and you know, I've kind of come to this realization for where we are, and again, there's no one right way to do this, is, "I'm going to stay and fight for this home, because I'm going to have control over how things are done. I'm going to put in preventative measures to reduce the likelihood that things happen." But I'm sure you can relate to this, and as I, you know, as well as I, but no home is perfect. So, even in my current home, things still go wrong. Despite the best of my ability, we still had a pipe burst—despite winterizing. And the difference between then and now is that I am far more proactive. I catch these issues sooner. I know how to deal with them correctly, unlike early on when I made every mistake in the book and trusted all the wrong people. So, I think this is super, you know, powerful what you're saying there, because for some, staying is the best option for them, and for some, leaving is the best option. And whatever you do, you know, make your choice, and you know, give yourself some grace, because there's going to be mistakes no matter what path you choose, and you kind of related to that.

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Lauren Lowenstein

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No, absolutely.

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Kendra Seymour

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So, can I ask you then? Because I know you've talked about this before on Instagram. One of the things that comes up all the time is the impact this has on your relationships. So, we've talked a little bit about physically just how life-changing this is. It's financially devastating for most people. But how did that impact your relationship with your husband, and your friends and family? Is there any tips for people who are going through that? Because sometimes we see one person in a relationship who really is the bearing the brunt of the symptoms, and maybe the other person isn't receptive, or they have a parent who isn't receptive. Any insight or advice?

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Lauren Lowenstein

15:58

Yes, absolutely. I think it's really important to talk about this because, you know, I like to say that that mold will either financially devastate you, which you know, it does to so many, or it a lot of the times, you know, destroys relationships. And people even go through divorce because of this situation that's so heavy, and the finances that implicate with, you know, the relationship aspect as well, and it can be crushing. So, you know, I'm blessed and fortunate that my husband never doubted my symptoms. I was very sick, and that was obvious. And so, you know, he did everything to support me trying to figure that out. But that doesn't mean that we didn't have our fair share of chronic illness weighs on relationships, because one partner is bearing the brunt of everything and carrying that load

for the family. And so, you know, a big part of it is that, you know, a lot of people may think, or a spouse may think, a partner thinks, "You know, if mold is really the culprit here, it would be making everybody in this home sick. So it can't be that. And I don't really believe that. And you're, you know, you're just chasing something that's not there, because I'm perfectly healthy."

And so, the one thing I really try to bring so much awareness to in the way that I deliver it on my social media is that there's a reason for that, and that reason is really your genetics and how your body is able to handle these toxins once they come in and your immune system turns on—and whether or not your immune response handles it properly or it doesn't. And when that happens, you are stuck in this state of chronic inflammation. And so, there may be one person in the home that is not affected in that way, and they feel perfectly fine, which was my husband, and he was perfectly healthy—obnoxiously healthy—but I'm so thankful because he, you know, was able to bear the load and then myself and my children. So, because I have this genetic susceptibility to mold, which is a biotoxin, genetically, you know, I passed it down, and my children have it as well. And so that explained why we were so sick. So, but still, once we came to that conclusion, it was hard, because here he's not sick, and we are, and he wants to help us.

But, you know, the thought of losing the majority of things in your home, and being displaced from your home, and navigating everything that that entails when you're not sick, is hard to wrap your mind around. And then the finances and everything like that. And so, what I try to encourage people is that, you know, maybe look into...and I try to provide resources of this is how you can educate yourself on the genetic aspect of it, and what that means for your partner, for this person, and why they're having symptoms and you're not. And just being supportive for them because it's really hard mentally to carry yourself through this, especially when you don't have that support system, and people don't believe you. And, you know, I had friends and family that loved me dearly, but started to think that I was a hypochondriac, and, "You need to stop taking your kids to doctors so much you need to just stop." And, you know, I would have loved to do that, and that just wasn't the case.

And you do everything you can, you know, for your kids, but when you're also suffering, it's really hard to try to get yourself better and take care of your family. And so, I would just, you know, don't call someone a hypochondriac, hear them out and entertain the idea of, "Let's test our home. Let's make sure that the indoor air quality is safe and that's not affecting them, even though it might not be affecting me." You know, even if you don't have a genetic susceptibility, mycotoxins, and endotoxins, and everything in your environment is still a carcinogen. It's still extremely dangerous for your health. And so, just because you're not susceptible or symptomatic doesn't mean you should live in it.

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Kendra Seymour

20:27

Right? Can we talk for a moment about a mother's intuition? Because I know you can relate to this, as can I, that feeling that you know that there's something else going on in your gut, yet you're being told by doctors, or you're like, "Okay, maybe I am overthinking this or

overreacting, you know, here." But you know in your gut that there is something else going on. Did you...was mother's intuition, something that kind of nagged at you? That kind of forced you to keep looking?

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Lauren Lowenstein

21:04

Absolutely. Oh yeah. I mean, early on we know—looking back—even our oldest, we brought him home into a moldy home. It wasn't this home, but now that we know, and we're aware, the home that we were in when we started a family had extensive water damage, and we just didn't understand it in its entirety at the time. So, for the majority of his life, he's had a lot of health issues, and my intuition always told me, "Something's just not right. Some things aren't adding up. This isn't normal." And that was hard because I would go to providers and they'd kind of be dismissive, or say, "This is normal. We'll or we'll just watch it, it'll be fine." And even my husband, you know, was like, "It's fine." You know, he's not a mother; he wasn't with them all day, every day. And, you know, our moms as well, it was like, "Would you just calm down? Would you maybe just don't overreact about every little thing?"

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Kendra Seymour

22:14

You get off the internet. Yeah!

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Lauren Lowenstein

21:04

You know, I would love to not, but, yeah. I think there is something to be said about that. It's just, there's a mother's intuition of, "Something's not right here, and I don't know what it is, but I need to figure it out." Because you sense that. You sense that you know your child isn't this happy, healthy, thriving child that they should be. And I mean, children should be, they should—if they're not, there's some root cause. There's a root cause going on. And, you know, I wish I would have known to look...

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Kendra Seymour

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That's my next question. So, looking back, what would you have done differently?

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Lauren Lowenstein

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Oh, gosh, It's...there's... I feel looking back, differently, had I known, you know, that environment plays an issue, I would never buy a home without an ERMI or a thorough mold inspection. And making sure to vet those inspectors, and making sure that they're properly licensed, and, you know, implement all those proper protocols that they should. I know now that there are mold dogs that are really good at what they do, and I would even, you know, utilize services like that to help identify where there could be areas of concern. I would also never buy a home or go into a home without checking this, you know, what is the HVAC? What is the HVAC compromise? What does that look like? Because those are the lungs of the home, and if those aren't healthy, you know, how can the people inside of it be

healthy? I used to be guilty of thinking, you know, a little mold never hurt anybody. It's normal, right? It's like an organic...it just happens, because it's everywhere. But people need to understand that even though it is everywhere—we can't avoid it. We don't live in a bubble. If you're genetically susceptible, there could be possible triggers that, you know, completely compromise your health, and there are ways to diagnose that and properly treat it, so that you can start to tolerate these toxins in your environment—and it's not always overwhelming to your immune system.

I would have pushed providers harder for root cause, especially for my kids, who had every single classic symptom of brain inflammation, you know, otherwise known as PANS and PANDAS in children. And knowing that, you know, if you're running from provider to provider for different systems in your body, and symptoms that's a huge red flag of chronic inflammation. So, getting to the root cause. Starting with the environment, not ending at the environment when you're trying to get a diagnosis. And know that, you know, if all of this is happening, your body's trying to speak to you. So, I think just knowing that now...and that's what I try to advocate for, is that I want people, when your body's trying to talk to you like mine was, you know, four years ago, five, six years ago, I wish I would have listened then, because I wouldn't have ended up with intense neurological symptoms, and atrophy in areas of my brain, and a traumatic brain injury just because of what it did to me going undiagnosed for so long.

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Kendra Seymour

25:48

Yeah, and I want to reiterate something for people listening, because I made the same mistake. A home inspection is part of your home buying process, but a home inspector is not the same thing as an indoor environmental professional; or an IEP. I know when we bought our first home, I hired a home inspector. I thought I did everything right. And when they found moisture in the basement (we lived nearby), and they said, "Swing by after work." And we did, and we had arranged for the sellers to fix that, and I'm sure they hired just a handyman. And I'm standing here with my husband, and our realtor, and their realtor, and this person who just ripped down a wall (what we now know was Stachybotrys). And there...I remember thinking, like, "If this wasn't safe, we wouldn't be standing here. But they're standing here, and they do this all the time." And we didn't know in the state of Virginia at the time that there was zero regulations. That, you know, anyone could tear this stuff out. And yeah, it should have been a red flag. But, you know, the reason I always ask people like, "What would you have learned?" I'm a big fan of learning from mistakes, and, you know, hoping that I can help others make fewer mistakes than I did in the journey. So, to that point, if you're listening and you want to know how to find a good IEP, because folks listen up—not all mold assessors are good. In fact, I'm going to probably get crucified for this, but I would say the majority are not who you want to hire. They'll come in, they'll do a few air samples from the center of room, and you know...

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Lauren Lowenstein

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I'm going to back you up on that.

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Kendra Seymour

27:22

Yeah, and that is not what we're talking about when we're talking about a thorough assessment of your home. So, if you go to ChangeTheAirFoundation.org, you go to our Resource tab, literally, the first tab section is Start Here. You click on that for mold and water damage. We will take you through how to find the right IEP, what to look for, what to avoid, red flags, even remediation, and we go through the whole process,

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Lauren Lowenstein

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I direct people there all the time because...

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Kendra Seymour

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Oh, thank you for that. Yeah.

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Lauren Lowenstein

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I mean, it's such a valuable resource. People come to me all the time, "How do I know my IEP is, you know, is good? How do I know all these things?" So, yes. Change The Air Foundation has such valuable resources to help people know what to look for and make sure that it's, you know, it's done properly.

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Kendra Seymour

28:07

Yeah, so I know you do a lot of advocacy now. And so, let's start kind of how you went from just healing your home, and your family, and your body to now having really national coverage, because you got picked up on Newsweek, you have a huge Instagram following. Like, how did that happen? I mean, you've had a real go viral with 10, you know, 10 million plus views. So, can you talk to us about that shift and how you've now kind of spent some time really advocating?

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Lauren Lowenstein

28:40

Yeah, it's been wild. I think I, early on, you know, through this, this journey of chronic illness first, and then the diagnosis of CIRS. And I knew—I don't know what it is, but, like, people need to know this information. I don't know how I'm going to do it; I don't know what that looks like. And early in my healing journey, it was, it just weighed on me, you know, I feel so passionate about this, and I want other people to be aware. And so, at the time, I just, I shared a reel kind of my journey, you know, of mold toxicity and my symptoms. And from there, it just kind of slowly started. And then, eventually one reel took off. And now there's a few of—one of them having almost 30 million views. And that was just, I think it resonated with so many people, because mold doesn't care, you know, doesn't care where you live. It doesn't care how much money you have. It doesn't care your

status. It doesn't care about, you know, your gender, your age. It just, mold affects everyone.

And so, a lot of people assume that I set out to have a career in the field, and that was not that wasn't my intention. My intention was just share, bring advocacy, let others know who are in the place that I was, because it was such a dark difficult place—that this might be your issue. And there is so much healing in that, and so I couldn't be more grateful for it just kind of fell into my lap and it sort of happened. I feel purpose and passion behind what I do. And I've been told by many followers that, you know, I trust a mom who's done her research over a provider these days, because, you know, that's essentially what I've done. I've just...I've dove deep, and I try to provide science-driven, data-driven information to people that they're just not getting elsewhere. And so, you know, I want people to know that healing is individualized. If you're struggling long-term, you need to reevaluate what's being missed, what's being overlooked. And that's kind of where I try to fill in the gaps for my clients.

So, it turned into just the awareness that was brought to my account, and then people searching me out for help. And I just kind of slowly started helping people, you know, advocate with your provider, ask them these questions, push for these tests. And, you know, I've tried to educate myself on inspection, remediation, testing, and helping guide people through that aspect of, "Hey, I'm so overwhelmed, I don't even know where to begin." And I know that feeling and we, you know, at one point in time, I said to my husband, I'm like, "How is there not someone to just tell us what to do? Because I don't know what to do. There's all this information, and I don't know what our next step should be. I don't know what the right one is. I don't know." You know? And there's so much fear. There's so much fear out there. And so, I really try hard to take the fear out of it, but give actional and practical steps forward, because a lot of people make these decisions out of fear—and they're big decisions. And so, I don't want people to make decisions out of fear. I want them to have the facts. I want them to know that, you know, we lost everything in our home, and if we had to do it over again, I wouldn't do it that way. There's things that I know now that, you know, and so, I just, I try to use my experience, my research, and continue educating myself by getting certifications and trying to just be able to broaden, you know, my knowledge, so that I can continue sharing it with others.

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Kendra Seymour

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That is amazing and something that I so appreciate and relate to. One of the things I always say is, you know, "Research before you react," because I understand the heightened emotional response and the fear that comes along with that. And I also understand kind of that analysis paralysis, meaning you're so overwhelmed with information. A lot of the times it's contradictory, right? "How do I do this to my home? Do I need this? Do I not? Should I just put in this UV light and that's going to fix that problem? Or do I not?" That people make no decision. And so, one of the things when people, you know, call the foundation, let's focus on your next step. If you focus 10 steps down the road, sometimes it can be very overwhelming. And what's hard is...and the reason I tell people to research before they react is because you have to become your own advocate, right?

No one is going to care about your health or your home as much as you. So, if the doctor misses the diagnosis or the remediator screws up, you're the one left living with the consequences. And it's not meant to overwhelm people, but I want them to get a sense of empowerment. Your resources—we've broken it down, we've made it accessible. We try to do that at the foundation. Really give people research-based, step-by-step, bite-sized information. And know that, you know, at the end of the day (and I think I said this earlier), but, you know, you are going to make mistakes. I look back, and there's things I too would have done differently, but you can't dwell on that. You did the best you can. You make the best choice and you move on. You try to make research-based decisions, informed decisions the first time, because you'll save yourself some time, and money, and headache along the way.

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Lauren Lowenstein

34:32

Yeah, the money...the money is a big one. Yes.

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Kendra Seymour

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Yeah. So, that is so important. Now, I know we're out of time. Because you have so many resources, and I'm sure people are like, "Well, I want to know her Instagram handle." If people wanted to reach out to you or had questions, how could they find you?

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Lauren Lowenstein

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So, you can find me on Instagram. I'm Thebiotoxinlady.CIRS, C-I-R-S. And my email is Lauren@thebiotoxinlady.com. And I do consultations with people. I have a mentorship group that's launching this week. And so, if you DM me, if you email me, I really try my hardest to get back to everyone as best as I can, because I to know the desperation that goes with needing guidance. And so, that's where you can find me, and I would love to help make your journey a little less overwhelming, or help you advocate to get answers for your health.

KS

Kendra Sevmour

35:39

Yeah, and we'll link to those in the show notes, so you don't have to worry about memorizing. You can just click into those notes and find Lauren. Wonderful. Well, thank you so much for being here, for sharing your story, for your continued advocacy spotlighting this because it is that an overlooked health issue that is impacting everyone. So, I appreciate your time today.

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Lauren Lowenstein

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Well, thank you. Thank you for what you do as well. It's equally, you know, we're all linking arms to try to make changes together. So, thank you for having me.

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Kendra Seymour

36:11

Absolutely. We're all in this together. And if you found this interview helpful, do me a favor head on over to ChangeTheAirFoundation.org, and sign up for our newsletter, because it really is the best way to get great information like this interview, free downloads, step-by-step help directly to your inbox. Thank you so much, and we'll see you next time.