

Oral History with Jane Acem

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Interview of Jane Acem

Session 1 (5/31/2019)

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VAUGHN: Hi, Jane, it is May 31, 2019. This is Rachel Vaughn with the UCLA Center for the Study of Women speaking with Jane Acem. Thank you so much for taking the time to do this interview with me.

ACEM: Thank you for the opportunity.

VAUGHN: Can you begin by telling me a little about who you are and where you're from?

ACEM: I'm forty-two-year-old woman from Cleveland, Ohio. I've lived here the vast majority of my life; I'm just a normal person. I spent a number of years working until I became fully disabled, and now it's kind of up in the air what direction life is going to take given the circumstances. I'm working, doing the same thing every human canary does—I'm looking for a place to live. So, I guess I'm currently just trying to make life work.

VAUGHN: You mentioned a few terms just now. Can tell me a little bit more about those terms? You mentioned the word disabled; what has your experience been like?

ACEM: Just in general? I'm currently disabled. I've had chemical sensitivity my entire life; I didn't know it wasn't normal until I was in my mid-twenties. But that was always a factor—I just kind of worked around it and toughed it out. I made myself even more sick trying to do that. When I was about twenty-four, everything started to get really (tape skips). For the last maybe fifteen years or so, I haven't been able to hold down just one job. I have to hold down three part-time jobs in different environments. It was a struggle to find work that would accommodate the chemical sensitivity. From there, the pile of other problems I have—Graves' disease, among other autoimmune issues—have cropped up separately. I now have pretty apparent signs of Marfan syndrome that didn't become obvious until recently. I have physical disabilities beyond just even the invisible things at this point. I have problems that are apparent; I have issues seeing and driving. I was an outdoor landscaper for a long time, because there was air outside, and I physically cannot even do that anymore. It's gone from one kind disability where I could at least make myself accommodations to another where I can no longer accommodate anything. There is no accommodation that will work. So, I'm fully, fully disabled at this point physically—I couldn't hold down a regular full-time job if my life depended on it.

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VAUGHN: You mentioned the term canary; could you talk a little about your use of that term?

ACEM: It's a "canary in a coal mine." I learned the term probably about fifteen or sixteen years ago when I was looking for people like me. I was getting very sick at work; I worked with a couple of women that everybody looked at like they were crazy, because they were in full-mask

respirators in this building. All I could smell was the toner from the printers and the pesticides they would apply every month. And I didn't know. She would say, "I don't feel well," but I thought, "It can't be making us that sick."

It's crippling, it's absolutely crippling. We are the human canaries in the coal mine, and we are the first people to get severely ill with the slightest chemical exposure. It goes back to that analogy where they would send the canaries into the coal mine to find carbon monoxide and other gases. If the canary died, you didn't send in the miners. It's all set. For the multiple chemical sensitivity community, this is how we self-identify. If we're going in and getting sick, then it's going to kill you guys.—it's just not going to happen as fast, maybe. You'll be in the black lung lawsuits; you'll be the asbestos-sick people. You'll be the people who get cancer eventually, but your health is going to suffer and you'll have diabetes in the meantime. We just need the emergency room now, if we survive it.

VAUGHN: Tell me about that last point you said, if you survive it in the emergency room. What would be the barrier of going to the emergency room? Why do you feel that way?

ACEM: If some of us get sick from the emergency room, we won't go. Emergency staff doesn't know what to do with us. It varies; there was one trip where I was with my husband and was formally diagnosed with multiple chemical sensitivity, with an ICD 10 code. It was over Halloween—it was paint fumes at work, and my boss got everybody painting whatever. I have arterial blood gas results showing organ failure for my kidneys and my heart. The ride to the emergency room was enough air to take it down a notch, but they had no way to intervene; I could have died of a heart attack. I'd gone back to work like it was normal.

The emergency room can actually make you more sick because of the cologne and the perfume and everything in there making the situation escalate again. I've had that happen with doctors wearing Axe body products and Old Spice. If that triggers my symptoms, they would say, "We'll go away." But I would respond, "No, no, no, come back and measure if you're going to kill me. Come back and measure it so we have some useful information for other people."

People go in, and they get sick. You have repeated anaphylaxis, and (they) keep handing (you) steroids as if there's some big mystery? No! If you keep having a person reacting, the steroids are akin to putting a Band-Aid on for a few seconds in terms of inflammation, but they are in the long run hurting this person. Conventional medicine does not appreciate that these substances are really, really damaging. They are more damaging to some of us than others. So if you go to the emergency room, you can actually be compounding the problem. But if your heart's failing, or your kidneys are failing, what choice do you have?

[00:07:08]

VAUGHN: You mentioned that you went to the emergency room, this one time in particular when they formally diagnosed you with MCS?

ACEM: Emergency room is glorified triage. They did the testing immediately. And they do supportive care; they either admit you because they have to, or they refer you to somewhere else.

In my case, he referred me to a primary care who was like, “Oh, you have multiple chemical sensitivity.” This was eight years ago, when the ICD 10 codes did not suggest that you were a psych patient for having MCS—this was when MCS was actually temporarily acknowledged to be a real thing. She just looked at me so matter of fact and said, “Oh you have multiple chemical sensitivity.” This is a major world-renowned hospital. I about fell off my chair.

VAUGHN: Tell me more about that moment. What did it feel like to have someone say that in that context?

ACEM: I froze. I was like, “Oh my God.” Because for years, you could tell doctors this, and they would ignore you. I've had the good fortune of having doctor relationships where—at least the majority of them—I understand that I need to say things in a neutral way, and they treat me neutrally and don't act like I am a head case because I'm saying this. But I was still shocked because this doctor in an absolutely massive hospital was saying to me, “You have multiple chemical sensitivity.” And I said, “Yes, I know, I do. It's been debilitating for years.”

It took my breath away to actually have them say that out loud. And then I started breathing and was immediately frustrated again because I realized that—particularly with the larger hospitals—the way that the healthcare industry works limits them from being allowed to even write a letter of support. This is a disabling condition, and throughout all of this, I tell my doctors, “You are going to get paperwork from disability, please just send my records and ignore it. And please don't judge me.” They're usually pretty good about doing that. But if I were to ask them to write a letter, they might reject my request.

One time for housing accommodation, I asked for a letter but the doctor was like, “I can't help you with that.” It's partly the busyness of it, and it's partly I think because they don't want to have their name on anything that recognizes that MCS is real. It sort of takes away from what they do for a living. Multiple chemical sensitivities is as political of a disease as Lyme disease is. If there's no solution that they can offer you immediately, they loathe to admit the impact that it has because there's just nothing they can do about it. They can be called quacks; they have to maintain a reputation. So, there's just little you can do.

This doctor had said to me “There's got to be something we could do about this.” She was racking her brain, you could see; she was like, “I know, we have an environmental wellness clinic here somewhere.” Well, we did—two years prior to that—and it closed down. It mostly focused on children, a lot of the toxicology departments focus on children not adults, as well as work and occupational exposure. It's like you have to be so debilitated in an obvious way before they will deal with you. They don't deal with low level brain damage from chronic carbon monoxide exposure, you have to be facing a gas explosion before they'll deal with you as adults. Otherwise, it's a referral to allergy. I about fell off my chair, because this is validating, and this is huge, and this is actually happening in this massive hospital system. But at the same time, it was kind of like, well, this is completely useless.

[00:11:19]

VAUGHN: In terms of helping you?

ACEM: In terms of helping everybody, in terms of helping everybody. I was a patient advocate for a long time; I've done a lot of work with individuals who have this kind of problem to work with language to communicate with your doctor—see where you can get. For example, go get all seventy-two of the organ systems diagnosed with the appropriate problems—then maybe you can go get on disability so that you have at least something while you figure out what your next step is.

VAUGHN:

So, what you're saying is that you are uniquely qualified in that regard—having occupied that particular job—to navigate this much larger medical system?

ACEM: I would say we—and we're trying to. I taught medical students for a very long time. And when I say that, I don't mean I have a teaching position. I'm the patient instructor and there's a teaching associate. You get to work with the residents and the medical students. When you're a patient, you end up seeing them on the flip side, so you learn a lot. I ended up seeing what they're facing and knowing what their limits are. This enabled me to understand them a bit more clearly from point A to point B as a patient. In the long run, if you can make it easier for other people to interact with the doctors, that results in better outcomes.

We should be able to count on nurses and social workers, but they're being tormented too. There's too few of them, and they're underpaid. All of the problems that go with the nursing staff—we need support, patient advocates need to be paid. They need someone to mediate between the doctor and the patient just to get better outcomes. You become a data point as a patient, at least with the way that they're collecting data now during every visit. And if they're going to be collecting data, we should have an outcome that points to "environmental illness is a real thing for many people, and we really need to do something about this already." Every interaction you have with your doctor is an opportunity not only for the individual to get somewhere with their own health, but for you to help shape medicine. You are a data point. It's all part of this long battle.

My experience has been very, very useful and helpful. It is so frustrating, and it is so depressing. How much of the mental health burden is all of us being chemically sick, and how much of it is dealing with doctors? You get a separate form of PTSD (post-traumatic stress disorder) from coping with doctors who deny that you have a problem. On top of that, when you're female, you are instantly discredited as a head case—"You're just anxious; you're just depressed. Or it's your hormones." Sometimes it is, but it's not what you think. A lot of times, it's just literally having the doctors deny your very reality. I've been able to try to help keep the situation be less depressing for other people based on what my experience is. You make use of it—if you get lemons, make lemonade. If you're going to have the crappy experience anyway, you might as well use it as a tool to do something good.

[00:15:10]

VAUGHN: You used the term head case twice now. Would you say that this kind of response and denial of your experience has been the most common of your experiences with a medical professional?

ACEM: I've had greater hostility from people who are not doctors. I've actually had what would constitute chemical assault from people who are not doctors. That's actually been a lot worse than the medical encounters. I've had experiences related to my other disabilities. I have a hiatus hernia, which really isn't a big deal, but when it happened, it was pretty terrifying at first. The emergency room referred me to primary care after also telling me to go see a psychiatrist. The—unfortunately female—physician who saw me for my follow up also wanted to refer me to psych because I articulated very clearly what this felt like. There was no effort at all to see what was going on. It was just pure (inaudible). In medical school you have complaints in more than one system, and (inaudible) you'd assume referring patients to psych was the right move. That's exactly what they were doing.

There's a lot of complaints from other people who have the chemical sensitivity—that people act like they're crazy or that doctors tell them “it is all in your head.” I know that people are going to minimize MCS patients. I have gone with girlfriends to doctor appointments for whatever it might be, and they're told, “Well, you know, maybe you need some counseling, have you tried cognitive behavioral therapy?” Chronic fatigue syndrome patients are like “Oh, that is such a real problem.” Chronic fatigue syndrome is a very common trigger for chemical sensitivity, so there is that overlap. If they're telling you “chronic fatigue is in your head,” it's like they're telling you everything wrong with you is in your head. So, there's this overlap about being reduced to a psychiatric patient across the board. It happens to everyone—everyone.

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VAUGHN: Do you feel that you've had any kind of formal recognition of MCS beyond this doctor? Do you feel that you've had any other acknowledgement of your symptoms in these cases in which you went to a formal medical practitioner?

ACEM: Yes, to an extent. I see an immunologist for a common variable immunodeficiency; I saw another immunologist before that. They feel that there's no point to the chemical allergy testing—though this isn't an allergy. Clearly, some of us do have allergies of different types, and some of them are way more obscure, and some of it's mass cell activation syndrome. Those illnesses are really not fun, and they're treatable. But when I say treatable, the medication is not enough. You really just need to avoid everything that makes you sick.

But in my personal case, my immunologist has said there's no point in doing allergy testing, but I want to do it in order to eliminate this as an allergy, because I do need to get somewhere in terms of my housing situation. I need to be able to provide a letter that says this, that, and the other. With a disability, you're always subject to review at any time. I needed to be able to say to them, I'm doing everything that I can to make sure I can get back to work. The doctor said, “No, there's no point in doing that. The only solution is avoidance.” I said, “Thanks for nothing dude.” He's validating, but he just thinks all I can do is to avoid this stuff. But that was as much as he can do. It's not that I have a positive experience so much as that they aren't invalidating; they treat it like

it's just a matter of fact—that's a lot less invalidating than having them tell you “this isn't real” and rolling their eyes at you, or whatever the case might be. And then aside from that, functional medicine is huge these days as a specialty, and they address toxins.

That's the trendy thing to talk about—the toxins in your life. They do address normal people with more conventionally understood diabetes and heart disease and that type of thing. We know all of these things are environmental illnesses, but not in the same way as multiple chemical sensitivities. They're constantly addressing toxins. If you say I'm really sensitive to x, y and z, they're going to believe you. One of my doctors in particular is very sensitive to things herself. They are allowed to keep themselves in a fragrance-free, sterile environment with safe cleaning products, and whatever. That's great for her. She's a doctor. She has a medical degree and a high-paying job, and she can afford to live in a better neighborhood with really fancy air filtration systems. It's a luxury that most of us can't afford, so it's not that she's validating so much as she's not invalidating.

The discouraging part is to hyper-focus on the genetic components of detox, which is fine. But they literally ignore all the components that make it more difficult for those of us who live with this. So again, it's not validating; it's just that they are not invalidating. That seems to be across the board. It's how you choose to take it, whether it's validating or just not invalidating. But I think the best we can hope for is that they are not jerks about it. That's a step forward in my opinion.

[00:21:15]

VAUGHN: You've mentioned the term chemical sensitivity, but also allergies. Can you walk me through and explain why differentiating between these terms is important?

ACEM: They are entirely different things. I know one woman through a chemical sensitivity Facebook group. We try to focus more on the science of the chemicals and what types of reactions people are having. This is because we're hoping to eventually put up a website that is useful to anyone and put in a very scientifically focused way. The admin has a T cell allergy, which is actually incredibly rare. It's a very specific allergy towards rubber compound and plastic. Several people have IgE allergies, which is different—that's a conventional allergy, like a tree pollen allergy, but you also happen to be allergic to your nail polish. Which is different from mast cell activation syndrome, which is comorbid with all kinds of things. Which is entirely different from having a genetic propensity for any thyroid disease or even type one diabetes—where there's an immunologic response that happens somewhere else down the line, perhaps in relation to all of these exposures and whatnot. It's multi-variant.

I happen to know that I don't metabolize estrogen very well. So it's completely unsurprising to me that xenoestrogen end up making my periods crippling. I have thyroid disease, and there's estrogen receptors on the thyroid gland. There's estrogen receptors all over the brain, and you're flooded with this, and genetically your body doesn't metabolize all of that extra estrogen. Then you have a problem.

Then there's the CYP450 (cytochrome p450 gene mutation that alters metabolism and controls expression of a) super enzyme family; some of us have variations on that and some of us don't. That's everything from mold to every drug you take, to components of certain foods, to chemical exposures we have on a day-to-day basis, and those are expressed in the brain. There's all these variables in there. The distinction is the person's ability to detoxify or not overdose. In my case, it's about not overdosing on everything, more than it is about being able to detoxify. For example, is it about (someone having) something that they can take an anti-histamine or inhaler for—and is that even enough because it's an IgE response, versus the T cell response, which is a different part of the immune system—you can't treat that. Aside from the fact that it's incredibly rare, there's just no way to calm down the immune system, which is different from mass cell activation. It's very poorly treated, and it's poorly understood, it's still new. I mean, it's only within the last five years that we've been learning about it, but it's clearly immunologic. And then there's these other genetic things that are ranged from everything from hormones to how your brain responds to any given substance that may or may not touch a dopamine receptor. So, it's so broad—but it's not all allergy.

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VAUGHN:

You mentioned the possibility of detoxifying. What does detoxification look like in your experience? For you what works or what has to happen to make detoxification possible?

ACEM: Sweating is huge. There are books that functional medicine doctors put out that makes learning about detoxification fairly easy. You just assume that if you're having these problems, you don't detox well. There's specific little nucleotide polymorphism that we can all inherit, that affect how we produce glutathione. There's different nutrients—a broad range from broccoli to garlic—and all of them act differently. You can supplement these different components like alpha linoleic acid. You can take milk thistle, and that gives a different effect. But your liver has to produce this for you to detox anything and those of us with broken variants—we don't fare well. You don't even need to have the genetic component. You don't need to have that list variance for it to be a problem for you because we live hard. We go home, we watch TV or go on the internet, but physically, we live in a hard environment. So even a person who doesn't necessarily have a propensity for anything can end up getting horrible migraine headaches with their elevated cholesterol. They're just generally feeling like crap all the time, because they're not making enough glutathione. There are other enzymes that are supposed to break down chemicals and interact with all these little proteins throughout your body. Sometimes those just don't work for various reasons, and when you take medication to put a Band-Aid on one problem, you can be creating a problem down the line. Your kidneys need to function well in terms of cleaning up the aftermath, but if a medication is taking away the ability of your kidneys to excrete all this stuff from your body, then you're not detoxing. You're not eliminating—through urine and sweat—the byproducts we're exposed to every day. Fiber in your diet is just as important as anything else. By in large, people don't get enough fiber in their diet to detoxify. There's a lot to detoxing, but it's important to sweat, exercise—do whatever you can to just make sure that things are moving out of your body properly.

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VAUGHN: Earlier, you mentioned that you were medicating away certain symptoms or experiences in your twenties. Was there a point at which you felt you had to stop on medication? Or what has worked for you, and what have you decided to do away with?

ACEM: That decision was made for me. I was so depressed and crying all the time. Birth control helped and I was like, wow. And then birth control started causing me problems. I ended up needing intensive care for forty days because my body cannot handle any extra progesterone. It just can't. So I spent forty days broken up over the period of the year in intensive care over this.

VAUGHN: What was happening? What was the catalyst that sent you to intensive care?

ACEM: My bowel seized up—my colon stopped working to the point that I was vomiting up something like garbage. I smelled like I was vomiting feces, because my food would not be digested, which made me hungry. My brain was still getting the signal that I'm hungry. But literally, you could watch me, and you could feel where the stool had stopped moving into my descending colon and no laxatives were working. So, I would just be doubled over in pain and fainting. I would go in and tell them that I really think it's the birth control pill. But my army of male doctors said "No, no, there's no way; it's not the birth control pill." Well, I stopped the birth control pill, and the problem went away. But I'm sure damage was done. That was the first; and then second, it was hard to cope with all of this. Life has its own stressors besides just being sick and besides just work.

At this point, I'm raging. Something's wrong with me and I'm raging. I thought to myself, perhaps this is hormonal rage, but I don't think so. So, I took some Cymbalta. The only reason that I tried this Cymbalta is because I was using diazepam as needed just to calm myself down. I would find out years later that I was showing the early signs of thyroid symptoms and didn't know it. But I would react very adversely to chemicals, and the people in my life, the people that are near and dear to me—the people that I choose to keep in my life—are the ones who could point to anything and say, "you were just at work, and they were just painting again," or "you were just around nail polish," or, "We went to the mall; no wonder you feel dizzy." They acknowledge that these things are probably very real variables.

I'm on the Cymbalta trying to make myself human because the doctor bullied me. She told me point blank, "I'm not going to give you your diazepam." Keep in mind, a bottle of refill would last me three years. I'm not a person who uses substances willy-nilly. The doctor said, "I'm not giving it to you until you take this Cymbalta." I said to her, "I tried that before, and it didn't do anything." They gave me twenty milligrams the first time and I told them this dosage isn't helping. I'm not going to take these risks if it's not even going to do anything. Well, she pushed me, lied to me and told me all that was available was thirty milligrams. I knew that was a lie, but I also knew I had to do this. I had tardive dyskinesia and thankfully it stays tame. It's been one of the biggest landmines I have to deal with in terms of dealing with doctors. This is because they don't know that allergy medication will trigger it. Anything that touches serotonin or dopamine receptors will trigger it. I have this slew of health problems. That was the beginning of the end of me using medication to try to fix anything.

I do have a couple of things that I use now, but it's mostly supplements. I just tell the doctors to go ahead and read my hypersensitivity list. Because I've tried all kinds of things, and I've overdosed on painkillers, not that I've used many of them over time. They gave me Doloteffin in the hospital when I was bent over pain and passed out from that. I told them, I feel like this is a safety risk, I'm rolling off the table because you guys gave me this Dilaudid and it's too much. I can't handle painkillers without overdosing. So, it was just—medications are out. It's an experiment that never ever ends well. All it does is cause more problems, so I just don't take medication.

[00:32:30]

VAUGHN: You mentioned taking supplements and milk thistle earlier, I understand that milk thistle is for the liver, is that correct?

ACEM: Yes, it's generically used as a liver cleanse. However, it is actually a glutathione precursor and it's really useful.

VAUGHN: Has milk thistle been proven useful to you?

ACEM: My concern is that people are going to think "Oh, you are miraculously cured because you are taking milk thistle." No. I am functioning at a baseline level that is as optimal as it can be for me given that I continue to avoid further exposures. Milk thistle is not a thing that you can take it and miraculously cures you of your chemical sensitivity. It doesn't work like that. However, it is helpful to optimize what your body is capable of optimizing (inaudible) given the environment. It's a very useful tool and I would be worse off if I didn't do these things. So, it's just making things as optimal as they can be.

VAUGHN: Is this one decision made in a series of decisions that you have found helpful to minimize your symptoms as best as possible?

ACEM: Yes.

VAUGHN: Jane, can you take me back in time a bit and tell me more about Cleveland and your family background? Tell me a little about the earlier contexts of your life.

ACEM:

In general, or does this only apply to the chemical sensitivity?

VAUGHN:

Maybe you can start by telling me about your family's economic circumstances? What kinds of memories do you have of your home?

ACEM: I technically was born in Parma, because we weren't living near any other hospitals in the suburbs of Cleveland. We had one hospital downtown and then the one I was born in. My parents drove far out of the suburb for me to be born at that hospital. My parents bought a house

to live much closer to both of their families. I was born in the late 70s. It was the early 80s and the economy was different than it is now. It was possible for a couple to get married and for the guy to be the sole breadwinner. My mother clipped coupons, and she did craft projects to raise extra money to put a roof over the house while my dad went to work and made sure the mortgage was paid. It was relatively simple, and I grew up learning that "if you own a thing, you should know how to fix it." We would put siding on the house. Or, my father would say "It's time to get the roof done." Getting the roof done didn't mean that professionals came to do it. It meant we paid for the shingles and the nails and the tar paper and my dad did it. Or, if you needed the car fixed, why would you take the car to a mechanic? You can just fix it in the yard. So, I would say, middle class, working class, but what that meant in the 80s is not as bad as what it is today in some ways.

VAUGHN: What did your dad do?

ACEM: He worked in maintenance and maintained machines. He worked at various production plants literally assembling, disassembling, fixing the machinery they made; every machine would come up from manufacturing cars to baby diapers. The man went in if it broke, and he would fix it. That's what he did. It's like a glorified mechanic, but on a grand scale.

VAUGHN: I see, a mechanic on an industrial scale. Do you have any sense of the kinds of exposures he might have experienced in his work?

ACEM: Yes. I think of my dad with memories formed to smell. My memory of my dad was shaving cream and grease. The man sweated grease. I remember when I was four years old, he had to clean paint brushes and the fastest way to do that with what we had was using gasoline. He would tell me to get away from there because gasoline is terrible for you. If it gets on your skin, it's going to make you so sick, but he had to clean the paint brushes. So, whether as a homeowner or as a worker, he was covered in gasoline, grease, and various other lubricants and petrochemicals, you name it. His work required some kind of fuel or lubricant; he was constantly covered in it.

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VAUGHN: Did he ever experience health effects himself because of these exposures?

ACEM: It would be hard to know since my father passed away when I was nineteen. He would have been forty-two then so it was really difficult to tell. He didn't complain about headaches or anything. He seemed generally physically okay. So, it would be really hard to tell because he passed away while he was so young.

VAUGHN:

You mentioned that you and your family lived in a house in Cleveland or in the suburbs? What kinds of smells do you associate with that home?

ACEM: After my dad left, it wasn't moldy. There was a sewer in the basement since that was the way the sewer lines that were in our cellar was in the community. There are some pumps in

there, sometimes there's just a hole in the floor from the old plumbing, where the drain was and you'd just have to flush the drain periodically. Otherwise it starts to smell like sewer, which is methane. We had a big yard, and it was clean for the most part until you track the history of the laundry product. It was a very different house when I was a kid than when I was thirty-five and taking care of my mother fairly full time in the house. All of the neighbors' houses just reeked of dryer fumes floating through the air constantly. It's so thick, you could cut it with a knife.

VAUGHN: Are dryer fumes something that you react to?

ACEM: Yes, gosh, it's crippling. It is absolutely crippling.

VAUGHN: What exactly happens? Can you sense the fumes from far away? What's your threshold?

ACEM: I get sick from dryer fumes if it's anywhere near, whether you can smell it or not. It depends on the wind, the day of the week how many dryers are going in that location. While I'm stuck here, I have to stay with people since Cleveland, Ohio is so unfriendly to people, homeless people, and people going in their car. There's no option for me but to stay with people. I'm with a friend who is in a building where we can keep the windows open basically all year round because of the heat situation. That works and it doesn't cost anything extra. That's the only reason that I'm able to survive at all. The situation that I was in before was constant, where my neighbors would be running a marathon of laundry with all ninety-seven kids on the street, so you had soaked wet clothes and that type of thing. It's constant. How do you get far enough away? For me, I had to drive five miles away to go sit at the lake, but you have to go home to that.

This building that I'm physically in right now isn't quite as bad. I'm sick and I can feel this film in my mouth and my brain is cloudy. I have a tendency to ramble because I can't remember what I was talking about. I feel nauseous all the time. That's just based on a little bit of exposure coming in the window here and there because the washing machines are at the back of the building. At least there's a breeze. It varies, and then it varies based on product. One of the things that's really fascinating is that all of the people that I know with chemical sensitivity can pick out Gain from everything else. We don't know why some products are more toxic than others, but all of us get like shaky, tremors, weak, and vomit. Did they dump an extra bottle of poison in there for all of us to get sick on? It's just awful, so no matter how far or close you are to the exposure, you're equally affected. None is the only safe option. I spent under six months out in the desert away from all of that and it is astonishing how human I felt. I could think clearly. I could form a sentence without any issue. I could keep track of what I was doing. I wasn't tripping over myself; my eyesight wasn't impaired. I wasn't nauseous all the time. It's because I'm away from the dryer fumes and the fumes on people and Febreze, which is really just same set of chemicals. Being away from that alone was tremendous, and it tends to be for a lot of us. It's like we can tolerate a little bit of other things if we have to as long as we can avoid that one in particular.

[00:42:39]

VAUGHN: You mentioned Gain as one particular product that triggers your symptoms. What other kinds of products have been particularly bad?

ACEM: In general?

VAUGHN: Yes

ACEM: Oh gosh, it was Lysol. Lysol was my first exposure when I was four or five. My mother had children and she didn't have people to clean her house. It was the 80s. You still have that like that mentality that everybody pitches in so you don't think anything of it. But Lysol and Fantastik were spray cleaners that everyone used, and then everybody started using (Formula) 409 because that was trendy. Those in particular would cause me to faint and blackout and I thought everybody had the same reactions. To this day, I can't tolerate any of that; it just gets worse and worse and worse. Comet, with whatever's in that, or bleach makes me lightheaded temporarily. I just air it out, and that one's easier to air out at least, but I don't use bleach. I don't think there is a safe cleaning product. One of the most fascinating one to me is the line of Simple Green products. It was my first awareness of how bad greenwashing is. They are phenomenal degreasers, and do a wonderful job of cleaning; but that was how I found out I'm really sensitive to trichloroethylene because they made me psychotic. I couldn't figure out what was wrong with me; I was raging. If you ever had to take prednisone, you know you can get really irritable and it felt like that. So, I was wondering what was going on and I looked at this data sheet and found out that all of their products are loaded with trichloroethylene. They've changed the formula, and I have to tell you the formula isn't much better. I was experiencing these mood changes that were absolutely horrible. Thank goodness my housemate is slightly intolerant and is very tolerant of me using alternatives. I use water with peroxide, and a little rubbing alcohol if I have to, and I ventilate. Other than that, I use plain dish soap and water or baking soda to scrub the tub. Thankfully, I don't have to use all of the toxic stuff because some people believe that it takes all of that to actually get things clean. There's just nothing safe. There is nothing safe out there to use.

VAUGHN: Do you have reactions to essential oils?

ACEM: Yes. I didn't used to think that I did until a two week long experiment that went wrong. All the sudden I had insomnia, and I couldn't figure out why. I have cysts in my brain and that type of thing which makes life more challenging anyway. But we were using this lavender oil to help my sleep be more even, and to calm everybody down. My housemate got this diffuser running with a lavender oil in it and my insomnia got worse. And I thought to myself, you've got to be kidding me. So, we aired the house out and stopped using the lavender and miraculously the problems seem to resolve somehow. This was an essential oil that was supposedly notorious for calming and helping you sleep at night, but it was actually making my insomnia worse. Recently, somebody had told me that everything that goes into the environment interacts with other things. While we know this, I do not have any evidence about the veracity of this claim and I don't know the specifics.

Essential oils interact with the Ozone and the environment. That interaction creates formaldehyde. I'm sensitive to formaldehyde, which you cannot smell. Both my housemate and I

were getting agitated when I was running the diffuser. It had mild things in it – it was like deep soil with little touches of cinnamon. It was fairly innocuous, or I thought it was. Both of us were agitated and had insomnia, so I decided to stop using essential oils. Whether it was mood changes, insomnia, coughing—even really high quality essential oils—it just made me sick and my roommate sick. It is just not worth it. So, we aired the place out and used peroxide to clean. I wear masks when I'm around germy people because I'm immune compromised and it's just what it is. I just use plain soap to wash my hands, and call it a day.

[00:47:39]

VAUGHN: Could you please tell me what kinds of household products you reacted to when you were younger? Did anyone in your family smoke?

ACEM: Yes. My mom did on and off. My dad did. A lot of it was outside but we had windows opened. I'm trying to think if my grandpa smoked. There were a lot of smokers in my family at that time.

VAUGHN:

Do you remember reacting or having any kind of reactions to that smoke?

ACEM: Nope, I could be fine around the cigarette smoke. For the most part, I was fine around some of the stuff my dad would use, but some of it made me dizzy. I didn't think too much about it. The degreasers and paint would make me lightheaded, but I think it makes everybody lightheaded. The cleaning products were actually my big issue; the Lysol and the spray cleaners to clean the walls and the appliances. That was actually the hardest on me at that time, or the air fresheners they used in school.

VAUGHN: Let's talk about food for a minute. What sorts of foods did your family eat? Can you remember anything in particular?

ACEM: Meat and vegetables. Whatever meat was available at the grocery store and whatever vegetables my mom picked up. A potato or starch, like noodles or potatoes cooked in a frying pan. It was whole foods, for the most part. She wouldn't let us eat any dessert if we didn't eat our good food. She just cooked healthy, normal, like you're supposed to.

VAUGHN: Do you remember ever having any reactions to scents or certain taste flavors in the context of food?

ACEM: No, not a reaction. I had texture aversions but I never had an allergic or sensitivity type reaction. No.

VAUGHN: Can you tell me your earliest memories of reactions to especially these chemicals and cleaners in the house?

ACEM: Lysol scrubbing bubbles. They are fun to watch when you're a kid. Lysol scrubbing bubbles are the most fascinating thing; you can watch foam pop up. But then you're fainting, so you have to give up your foam bubbles.

VAUGHN:

What was your family's perception of your sensitivities to these products? Did they do anything?

ACEM: I didn't do or say anything about them. My mother is not an emotionally supportive human. My dad was much more so, but it didn't even occur to me to say something to him, so it was not his fault. I thought it was normal, and honest to God, when I was in nursery school, I had conversations with myself. I said, "Come on, tough out! Everybody else is fine, why aren't you?" I literally thought it was normal for people to blackout from using Lysol. I thought that was normal and I couldn't figure out what was wrong with my brother that he wasn't fainting. What was wrong with my mother that she wasn't shaking and sweating? I thought that I must not be tough enough. That was my actual thought process. I have no idea how I survived as long as I did given that was my thought process into my twenties. I remember my mother developing sensitivity issues. She used to wear White Shoulders perfume. She developed a sensitivity when I was a teenager. I remember thinking when I dusted my room and cleaned out the skin musk that I wore as a teenager, my sinus problems went away. That's interesting and I thought, "What's going on with mom that she's so sensitive to her own perfume?" But none of us could wear perfume anymore. I did feel a little better, so I didn't make too big of a deal out of it, but I questioned my mother's sanity. I thought we're just not tough enough. What are you talking about? It can't be that bad.

VAUGHN: What do you remember? Sorry (for interrupting).

ACEM: No, go ahead.

[00:52:27]

VAUGHN: What do you remember about her specific development of that sensitivity when you were fifteen?

ACEM: I was fifteen or sixteen. She would have been in her thirties. She started saying, "my nose is running, my throat is irritated." Or "It's making me sneeze. I can't wear my perfume anymore. I'm stuffy." She had these kinds of symptoms that almost look like an allergy.

VAUGHN: Can you remember any memorable, notable sources in Cleveland that emitted chemicals in and around your neighborhood?

ACEM: No, we were part of the suburbs. There's a farm at the end of the street, it's not huge but it's a farm. There are large backyards and tons of woods. On the other side of the woods is the hospital. A lot of people buy property here and just hang on to it forever. My stepdad currently lives in that house, and who knows who will live in it afterwards. That house has been owned by somebody in my family for forty years and it's true of most of those properties. There are no

businesses or industry right there and there probably won't be. So, it's just going to stay residential. Chemical emission wasn't an issue where we were at, at all.

VAUGHN: Earlier you mentioned a sewer in the house. Can you tell me anything else about the infrastructure of your house? Was the sewer unique to your house?

ACEM: As far as I know, everybody in the city had a couple different sewer setups. The way that these sewers were set up to these houses, that was just kind of what it was. Part of it was just to prevent seepage into the walls if there were heavy rains. People dug out their foundations and sealed everything up. It was what it was and people fixed their own stuff. It was not uncommon to see somebody digging around their house to get to the foundation to make sure it was sealed up. If the drains were full, we'll have a pump waiting in case it's a really heavy rain and the sewers backup, and that's it. We didn't really have any mold problems. We just managed it with a dehumidifier. Everybody always had a dehumidifier going to keep the dampness under control. You want to protect your house, that was mentality back then. You want to protect your investment, so everybody just took care of what it was. The sewer wasn't even that bad. My dad just flushed it with water, and it goes down and there's no problem. We had electric appliances, so it's not like there was gas fumes or anything.

VAUGHN:

Tell me about your school, or schools if there were multiple.

ACEM:

The schools were in the same area, so it was residential. There were no weird environmental issues in terms of water or anything else. The worst for my body was just the air fresheners, occasionally teachers' colognes and whatnot. The colognes teachers wore made me a little bit lightheaded and dizzy. People would make a joke of it back then, "Oh, they're wearing an awful lot of cologne, did they take a bath in it?" This was twelve-year-olds making fun of grownups for doing what they do. It's a different thing and a totally different attitude, because it's the anomaly and not the norm. Other than that, it was those disgusting little lemon scented air fresheners in every bathroom, which made me lightheaded and feel sick. We didn't have an auto manufacturing plant right next-door, or a paint manufacturer down the street or anything like that in the suburbs, there was nothing there.

[00:57:03]

VAUGHN: The air fresheners that you mentioned, were they the kinds that you plug in or the cone like, plastic, free-standing air fresheners?

ACEM: Yes, it was those cones.

VAUGHN: Okay, so your greatest memories of reactions were to isolated products, scents and fragrances. What was your highest level of education you finished?

ACEM: Some college; I have a couple years of college.

VAUGHN: What were some experiences of chemical sensitivities during your experiences of college? Was it the same type of thing you were responding to in that context?

ACEM: Yes. Again, the college wasn't near any manufacturing or anything. The restroom stinks like air fresheners, and occasionally somebody is wearing too much cologne. But other than that, it was pretty innocuous then.

VAUGHN: When did you first start working?

ACEM: When I was twelve, I got my first real paycheck that was not for babysitting. I was working for the company my uncle worked for. They were making airline terminals. Back in the late 80s and mid-90s, the airlines were just starting to get those fancy computers where they can print out the tickets right there for you. Your airline check-in lady could type in whatever and you can look at your reservation and whatnot. It was back in the days where everything was still massive. They needed help doing inventory, so I got in there. I was counting eight million little transistors and marking down 472 because it was inventory. But I also learned to solder; that was minimal. I learned to solder and built large crates to ship things. I was twelve, and came from working people, and I was eager to work, so that was my first job.

VAUGHN: What are some of the other jobs that you've had later in life?

ACEM: I have done just about everything. From working in fast food to regular restaurants to grocery stores to office work to clerical and water damage remediation. I'm a teaching associate. I worked for one of our local abortion service providers just doing clerical work. You name it, I've done it. Landscaping, roofing, I've had jobs on and off. I'm a jill of many trades but master of none.

VAUGHN: Did your illness affect your work, or any particular one of those jobs?

ACEM:

Yes. It became the determining factor of what I could do after a point in 2011, prior to nine-eleven (September 11, 2001 attacks). I've had doctors asked me, "Are you sure it wasn't the stress of it?" I'm sure because I started the job before nine-eleven. But it was like May of that year and within one month of this job working for this credit card processing firm. It was the best job I've ever had. It was close to home and I was making twelve or thirteen dollars an hour. They gave us a pay increase just for showing up. They gave us all a companywide pay increase. And we thought, this is the best thing that happened to us ever because this was a huge opportunity. Within one month of starting work there, I went from having normal periods to being so incapacitated I was in the bathroom every thirty minutes. Prior to nine-eleven, I was finding out how to file for FMLA (Family and Medical Leave Act), and I lasted about a year and a half because I did not want to give up this job. But that job was the beginning of the end. There were women wearing respirators and everybody there had either fibromyalgia or lupus or some kind of other autoimmune disease, or were on antidepressants. Everybody working at this job had something wrong with them. It was the beginning of the end for me. And I wondered if it's this building that was triggering these illnesses for all of us?

[01:02:04]

VAUGHN: Tell me about that. Did everybody develop something after?

ACEM: A lot of people would not have made the connection. There were a couple of women who worked in full mask respirators. Everybody just looked at them, like what are you doing? It ranged from migraines, headaches, or I don't feel good all the time, to serious diagnosis. One lady has lupus. Another one has Hashimoto's, another one's got fibromyalgia, a bunch of people have the diagnosis for chronic fatigue syndrome and some of them were in their sixties. It was a range of people, but not surprisingly it was mostly women, who had like all of these issues. They had been there for four years, six years, eight years.

In retrospect, there were traces in the conversations I had with some of the people outside of work since we stay in touch. For example, something simple like "I can't lose weight" and they didn't have a thyroid problem, but they couldn't lose weight and couldn't figure out what the problem was. It's hard to tell with some of them if it was in fact the environment making them sick or not. But it certainly wasn't ever going to help them get well if they were sick before they started working for the company. New people come in and they started having migraines. Every day, they have the migraine headache; every day it's something new. Everybody is always starting a new medication, so it just seemed like the environment was ripe to make everyone sick if they weren't.

VAUGHN: Is there anything that you can remember about the building?

ACEM: Yes, we were working in the basement. It's one of those buildings where you just expect that there is asbestos and you're not going to talk about it. There was no ventilation in the basement of this building. It was built in late 40s, early 50s because the heyday for the shopping strip that it's in was in the 70s. This was the first department store in the area. The credit center just rented this space because they were cheap. There was no ventilation barring the elevator doors opening and closing. There was no fresh air in there. It's a locked facility because it's a credit card center. There's constantly air blowing in, but nothing ever gets sucked out. There's not one window in the place. You can fart and the whole place would be—

VAUGHN: This was the credit card processing company?

ACEM: Yes.

VAUGHN: Tell me more about the job. What kind of work did you do?

ACEM: Literally, all of us typed. Either you're taking addresses or you're finding out where people live; hunting them down so that we can collect whatever money they owe. In some cases, we repossessed people's appliances. When people made a mistake, it would get spit out by the computer. My job was to go back and figure out where the mistake was made and send out the right letter. Everything was automated; every letter had a code, you just type in the right code, and the right letter automatically gets sent. Needless to say, the printers are running all day long.

VAUGHN: The printers were running?

ACEM: Incessantly, incessantly.

[01:05:56]

VAUGHN: Were you coming into contact with inks or dyes?

ACEM: We all handled the paper, but I was not using the printers. That was a whole separate section. But when you enter the company, it smells like a library. It's that constant running toner smell. It can be pleasant if you don't think about the fact that it's toxic. If you don't think anything of it, you just go into work and it smells like there's a constantly running printer in here somewhere.

VAUGHN: Was the toner a defining scent beyond not having the ventilation?

ACEM: That, and the pesticides.

VAUGHN: What were the pesticides for?

ACEM: They just smelled like ant sprays. Always, always!

VAUGHN: Did you ever have any knowledge about what they were spraying for?

ACEM: I didn't know if it was preventive. I know the area doesn't have cockroaches or anything. Parma is a suburb where we're paranoid about problems, so we're going to bomb it with DEET before anything happens. That's just how it was, so it could have just been like they were worried about the ants becoming a problem, so they sprayed.

VAUGHN: So, it was in a town where high use of pesticides spray or—

ACEM: Or green herbicides. Everybody nearby used lawn care maintenance. It's just what normal people do in that suburban neighborhood. It's a mentality where we don't want any weeds, and it was applied to everything liberally.

VAUGHN: You called this, "the beginning of the end." Was that the most memorable development of sensitivity for you in a work context?

ACEM: Yes, when I left that job, I just had to throw in the towel. That was when I knew for certain that it was chemicals making me sick because I would take the weekend off and I'd feel better.

VAUGHN: Can you describe to me in detail how you felt at work versus when you were away?

ACEM: When I was away, I felt much better. I started noticing at home I couldn't use my lilacs scented candles anymore. I was dating a guy who told me, "No, it is not normal to be sick just

from using Comet in your bathtub.” I asked him, “How do you handle the dizziness?” and said, “I’ll handle the dizziness this time.” He didn’t understand what I was talking about. So I asked, “Don’t you get sick from using Comet?” He’s like, “No.”

I started eliminating that and, aside from the dryer fumes which started to make me sick, home became sanctuary. I’d flush the apartment out with air and I would literally just sleep it off. And then I would feel human by Sunday. By Monday, I would go to work and I would feel like death warmed over four hours in. I would go from being a normal person being on Saturday to Sunday to being sick again on Monday. I dreaded work; it was horrible. I started nodding off at my desk; whatever broke had affected my sleep permanently. I no longer can function normally by the hours I get up. My doctors are joking that my body lives on California time. That’s actually not funny because it is actually true now.

I had delirium. I can’t tell you how many times I would go into work and I would have to type in notes about this account that I was working on, and I would catch myself somehow writing about my grocery list or whatever that was going on at home when I was working. I had actual delirium from whatever the environment was doing to me, and I would have to stop myself and correct it. My boss more than once came over and she very kindly adjusted my work schedule to accommodate whatever was wrong with me because I would be nodding off at my desk. I would go home on the weekend, and I could function normally. I wasn’t nodding off by my computer at home. I wasn’t nodding off trying to eat my lunch at home. It just became this night and day difference between me at work and outside of work.

[01:10:51]

VAUGHN: What other kinds of symptoms did you experience other than fatigue and delirium?

ACEM: The tearfulness and the mood changes. I would cry on the drop of a dime on the weekdays and I would go home on the weekend and be my bright, sunny, normal self. When I went into work, I would start crying if anybody looked at me the wrong way. It wasn’t depression; it was irritability. I’d been there for maybe a year, and I left. It was when I started interacting with (the) mental health care system. I don’t remember when I got on a FMLA exactly, but I ended up spending a week in a mental health facility of my own volition.

I was at work and something was happening to my brain. I felt like I was being pulled out of my body and wanted to yell at everyone. I felt so completely out of control. So, I told the HR (Human Resources) department, “I’m going to leave now because I feel like I’m going to like start throwing things.” She just looked at my face and said, “Okay, just get us some letters.” I left and called the county mental health department. I told them that I wasn’t sure if I should go to the emergency room or if I should go there but I need help bad, there’s something wrong with me. I left that environment, and immediately the problem went away, but they had me go into a facility. I confused the street names, but it was on different ends of town. It was an hour commute difference, and by the time I got to this facility, they said “We didn’t think you were coming.” I didn’t know how to explain to them that I got lost because my delirium was so bad that I confused these two simple street names of Detroit and Denison. For some reason, I couldn’t keep them straight so I was driving in circles trying to find this building to get there to

turn myself in. I didn't know if I was having a nervous breakdown or what. Of course, they wanted to put me on these drugs and I told them no because I slept. I told them, "I'm fine, why am I even here?" I was having these serious mental health effects from the chemicals at work. Years down the line, I find out that I am highly sensitive to endocrine disruptors, so now I know why. It was bad enough that I had this thing that looked like a psychotic break or something. It really looked that scary.

Not long after that, I left the job because it was undeniable that this place is making me sick. It has literally shaped my entire life since then. I can't take any jobs indoors for any length of period. I can't do it. I can't stay. I don't last. I start getting too sick. I start having overt symptoms. Or I'm nodding off or making mistakes. I'm just not even capable of working indoors. The indoor work that I have done since then has been dependent on the understanding that I am going to take a lot of breaks or I have to open my office window. It's been an uphill fight.

[01:14:41]

VAUGHN: Was that the first instance in which you received some form of support for what you thought was a mental health reaction?

ACEM: Yes.

VAUGHN: Did you feel better once leaving the workplace?

ACEM: Yes.

VAUGHN: How long did you receive support from the county mental health facilitator?

ACEM: I ended up seeing a counselor for a little while. I could talk about what was happening at work, but they always want to know what's happening in your personal life. It was like six months on and off, here and there. I'm a huge fan of therapy anyway; just go talk to someone, and find someone that works for you. It was normal for me to go in and seek counseling because my family wasn't perfect. Nobody was and life has stress, so go get therapy. I had to do outpatient appointment, it was six months after that. I saw them and the least of what we talked about was my work situation. I think it just takes a long while to make that connection to understand what was happening to me cognitively. At the time, we were talking about every other stressor in my life, including my mother, and not the chemicals.

VAUGHN: Do you mean not having the rapport that you wanted with your mother?

ACEM: In terms of the counseling? In terms of I felt better because I wasn't getting sick all the time?

VAUGHN: No, I mean, you said during that period, when you were talking with a counselor, you were chalking it up to things in the home or the dynamic between your mother and you?

ACEM: Yes. I was making the problems out of normal life circumstances because I didn't realize how much of it. I was on birth control at that point, and I noticed the birth control made me feel better. So, I thought it's just hormones, and I was minimizing it as hormones. As pissed as I was at my mom, and she was a jerk--I hyperfocused on the situational and social problems as if those were the reason for my stress rather than any physical problem.

VAUGHN: Rather than the work environment?

ACEM: Yes.

[01:17:40]

VAUGHN: Did you have any symptoms in this workplace when you started taking the birth control? What do you remember about that particular birth control and what kind of physiological response or responses were you having?

ACEM: I had a whoopsie when I was about nineteen, so I ended up on the pill. I just stopped taking it because I thought it can't be good to be on this stuff all the time. When I was twenty-four, I was in another relationship and it was at this job. I was concerned about getting pregnant so I started taking the pill again. It also had a bonus side effect because I felt more human at work. So, I noticed that there's a hormonal component to this and that was the beginning of my education about birth control. I went back on the first pill that I was ever on, which was Ortho Tri-Cyclen. It felt amazing the first time, it was great. A few years later, I took it for the second time, and I gained thirty pounds of water weight overnight. I was freaking raging and was acting like a lunatic. I was screaming at people for no reason whatsoever. It was just horrible and embarrassing. I called Planned Parenthood for how I was acting. I called and said this birth control is terrible. So, they switched me to Loestrin. It was back to this is the best thing that ever happened to me because my hormones weren't all over the place. It wasn't too much. So, that was beginning of the education about birth control for me. I learned what the birth control can do and it was weird how it was mediating whatever was happening to me in my environment.

VAUGHN: How long were you able to stay on that changed birth control before you started reacting to it?

ACEM: Around 2000, I took another break from the birth control. I decided if I wasn't having sex then I was not going to put this stuff in my body. It was probably around 2007 when I figured out that's what it was. My nurse practitioner suggested for me to get back on the Loestrin. The clinic that I was working at didn't carry that drug anymore, so I had to switch to Alesse. She had me on some other low estrogen equivalent and it wasn't the same. I didn't feel right, and I didn't feel good. The nurse practitioner left and the next one, they said "You're going on the Alesse. You're coming up on thirty years old, and I don't want you to have a stroke on me. I don't want that on my conscience." So, she put me on this pill and that's the pill that landed me in the intensive care because of all the progesterone. I was never on the birth control continuously, but the Loestrin and this alternative to Loestrin made it easy for me to watch my body respond differently to the birth control over time. It was in a matter of years that the same

drug that was fine before is now suddenly horrible. It was not working for me, and I was not feeling well so it became a problem.

VAUGHN: What are some of the reactions you had to these three different types of pills? You mentioned things like weight gain and change in mood.

ACEM: Yes, with Ortho Tri-Cyclen, you expect that. It's a common complaint about it. The lower estrogen ones are not supposed to be like that. So, I was surprised that I was not responding as well the second time around. It was the definition of malaise: I don't feel well, and I can't put my finger on it. It just felt like something isn't right.

VAUGHN: Did you have the same responses to Alesse?

ACEM: The change to Alesse was the nightmare. That was the one that locked up my colon.

VAUGHN: Okay, I remember you saying that.

ACEM: Yes, she insisted I take this progesterone only because I could have a stroke which she didn't want. It was the same manufacturer as the alternative to Loestrin. I knew I didn't feel good on that so I was really upset about starting this drug, but I didn't have a choice. At that point, that was the only birth control option that I know I could count on because condom failure happens. But the drug was causing my bowel to stop working just all together. People told me to just take a laxative. I was in intensive care and they literally gave me Golytely and there's Nulytely. I had to consume entire pitchers of both of them and nothing was coming out. They talk about gut damage being the underpinning of all these health problems for people these days. I know that they're right because my body just absorbs all of these laxatives. I weighed 103 pounds while I was there. A doctor ended up in sensitivity training because he accused me of being anorexic because I weighed 103 lbs and I had this massive distended belly. They loaded me up with laxatives, but nothing was coming out, and I couldn't eat anything so I weighed 103 pounds while I'm almost 5'8". That was not anorexia; it was the reason why I was in the emergency room. It was that bad, I couldn't eat and nothing was coming out.

[01:23:44]

VAUGHN: What was the breaking point with the credit card processing jobs?

ACEM: That was just about accepting that work was impacting my health that bad. Nothing that I was doing was making me better at the time. I felt better when I go home on the weekend. By then, I picked up a part time job at a coffee shop and an evening job in an auto parts store. I didn't feel as sick in those places as I did in that one. So, I said, "Forget it, I'm just going to give up on my fantastic high paying job." I just had to give up, and things improved somewhat for a while. I hit a point where I was like this place is making me actually sick. I am actually sick here. So, I had to leave.

VAUGHN: Did your co-workers know about what you were experiencing in the workplace?

ACEM: They did. I wasn't clear on the fact that it was the chemicals making me sick until after the fact, so it was not part of the discussion. All of them were ill and they were like, "Oh, did you get tested for lupus?" And, "Oh, you should go get your thyroid checked." People were recommending antidepressants that worked for them and that type of thing to me because we were all in this together and they could see that I was clearly having problems. They told me what worked for them, so it wasn't overtly, "The chemicals are making us sick." After the fact, they did stay in touch with a couple of people. I really felt like that was making me sick. Some of them have headaches or more minor things. They weren't quite as badly impacted, and it was enough that they could dismiss it, but I couldn't.

VAUGHN: What were your interactions with them like either before or after? Were they supportive in some way or was it more so denial?

ACEM: Yes, for the most part. The greatest hostility that I've had experienced were mostly from men.

VAUGHN: Do you mean at work?

ACEM: Yes.

VAUGHN: Do you mean hostility because you were asking for accommodations?

ACEM: I've never asked for accommodations necessarily. When it isn't going to work, I'm not going to ask for accommodations since I'd just quit the job. After leaving the wonderful job, my approach was to find jobs that would accommodate me. I spent fifty percent of my time outside in the autoparts stores. I take the trash out or working the windshield wipers, or I'm stocking the inventory so I'm out the back door half the time. I can also stand right near the front door, where there's a ton of air coming in, because I'm ringing up purchases. So, it was literally finding an environment that I could work in. I was working at the abortion providers office for a while. That was a problem because the schedule didn't accommodate me. They can only shift so much, and there was no air. So, I'm in this frigid, stale air with all of these people. They weren't wearing a ton of perfume or anything, but even just the soap in the bathroom at that point would make me sick. On top of that, I couldn't get air, so I was sick and eventually I lost that job. But I've never really overtly asked for a lot of accommodation.

For my last job, I worked for a Detroit water damage remediation company for a number of years. I would tough out being sick, but we were always allowed to have our windows open. It was considered partly accessible because my boss was just very unconventional. We worked with mold in basements and we would be carrying out things and bringing back contents that had mold on them or had to disinfect it. You ventilate as much as you possibly can. My boss would get headaches from certain things actually, so he understood. He allowed me and one of my other co-workers to share an office where we could keep the window open. We could make circulation work for us, but it wasn't so much that we went and asked for the accommodation. It was just acceptable to make an accommodation for yourself. So, it's not like I've fought for accommodations because I don't feel like that's a winning battle. I have decided to just go where I can work with whatever. On the flip side, that was actually one of the worst jobs I've ever had

in terms of abusive co-workers. You just tried to make it work. Many of us can go, and we can ask for special accommodations, and the needs aren't going to be met. Or, there will be enough of a cursory effort so that in a right-to-work state they can say we have made the accommodations that you requested; have a nice life. They can fire you for no reason, so there's very little recourse or feedback for the deliberately spraying of cologne in my office. One day, I finally said to my superior, "You realize that this is a disability, and I could go to the EEOC (Equal Employment Opportunity Commission) and the ADA (Americans with Disabilities Act) to file a complaint. I can make your lives really miserable. Or you can just ask Tony to stop spraying cologne in my office."

[01:29:49]

VAUGHN:

Is Tony one of your co-workers?

ACEM: Yes. I just made it clear that it was choice. After that, there's still the bathrooms which are going to be covered, and hallways are going to be a hot mess. But at least there was no more of it in my office. So, you can try it, but it's going to be this big long thing. How long do you want to drag that out? On the flip side, the problem now is future employers can see that you filed this complaint about your disability with the EEOC if they do a background check on you. Any employer can see that and choose not to hire you in the future. So, we are just a long way from people being able to accept that people who are disabled need accommodations. They must also learn to not discriminate based on that disability. We must assert ourselves enough to say you should accommodate our disability. I haven't pushed too hard on that. Honestly, my focus was keeping food on the table to pay my medical bills.

VAUGHN: You mentioned that one of your co-workers sprayed cologne in the office. Is this the co-worker who is denying your statements to sensitivity?

ACEM: Yes. I've had Midol left on my desk. They found the box of Midol somewhere and left it on my desk for me. They've said some very inappropriate things. But it was flexible, and he let me open the window, so I didn't push a lot of issues too hard. He left Midol on my desk in response. I work with these people who act like jerks, and I'm perfectly fine with the customers. My boss was like, "Why is she nice to everybody but mean to me?" I'm like, "Joe, you act like a jerk," or "Tony, you act like a jerk, you left Midol on my desk." So, I just walked over to his office and left the Midol on his desk and was done with that. There was a lot of sexist BS and whatnot too. I had to take in consideration the fact that I was extremely sick at that point; I had diagnosed Graves' disease. One of the things I didn't know about was that we were using thymol as a disinfectant. Tony was like, "It's natural, you shouldn't get sick! It's natural." He was making these stupid snide comments about how it's natural and clearly this is all in my head because these are natural substances. I have files that I would take home to work remotely, and I'm sick. By the time I put this stuff away from me, I'm suddenly feeling better. Thymol is an endocrine disruptor, and it is known to have effects on various components of the endocrine system. No wonder I was sick, so I left there.

Miraculously, I didn't have to take my medication all the time anymore. It was beyond the effect that the chemicals can have on the brain directly. They can affect the endocrine system, which has a really pronounced effect on your brain. Whether it's the auto immune response literally attacking parts of your brain, or the hormonal aspect, whether you have diabetes, or you have adrenal disease, or you have the thyroid disease, all of that. You can have polycystic ovaries. The hormone changes are going to affect your brain; blood sugar fluctuations are going to affect your brain. I was moody and I dismissed the Midol. I decided, that's fine he thinks I'm bitchy. Whatever, because I kinda was. You talked it out. You take the good with the bad. The good was that I could leave if I had to go to my doctor appointments or take care of my mother whenever I needed to and I could keep the window open.

[01:33:53]

VAUGHN: Tell me a little about your social life during this point of your life. Who were your friends? What were your hobbies? What were you doing in your spare time? What kinds of connections did you have beyond your work?

ACEM: My social life was pretty limited. It had been for a long time because I had a mentality that was like, "I have to work, but I don't have to socialize." I could try to go to the movies, but that's money spent, for one, and two I didn't feel well a lot of the time. And three, time has passed, and things are getting more and more toxic. So, in addition to me getting sicker, things are actually getting more toxic. So, going to a movie theater was not feasible. If somebody who washes their laundry in scented detergent sits in these chairs, then I'm stuck trying to find a chair that they didn't sit in. It just doesn't work. If I want to go to a movie with my friends, we have to wait until it's been out for a month and a half. So there's no people in the theater, so that I'm not fainting trying to watch a movie. So I can't go to the theatre, and it's hurt my social life. My friends are the people who understand, and while they are not always able to make their home accessible for me, they are willing to make accommodations.

Occasionally, we go to have dinner on a patio or go to a festival or something and they'll push me around in my chair at the Fest. We were at the Corn Festival, we were outside and there was enough air. My friends are also kind enough that if they smell something coming, they'll tell me to get away from here and help me move. We don't say this, but we understand, particularly given my inability to walk as well as I used to, I just don't do as much. I don't really have as much of a social life. A lot of my social life is text messaging, or phone calls, or online at this point. It is just so hard for me to just do anything. Even if they're willing to push me in a chair, it doesn't change the fact that I have postural orthostatic and an autonomic response to these things. I end up having blood pressure and heart rate changes when the stuff affects my autonomic nervous system that make it impossible for me to enjoy anything. It may or may not result in me needing to go to the emergency room if I continue to stay there. On the OSHA (Occupational Safety and Health Administration) Safety Data Sheet, they tell you remove to fresh air first if someone has a reaction. That's the rule of thumb for the chemical sensitivities, it's just "get away from it." So, not exposing myself to it in the first place is really just a big thing. As a result, I don't have much of a social life. I just don't.

[01:36:41]

VAUGHN: What kinds of changes happened to result in your use of a chair after the work experience that you described as the beginning of the end?

ACEM: I had the great job that I left, and then I had everything in between. I developed Graves' disease; it was so bad. The lab that ran my test was modern and updated enough that they were able to detect my thyroid hormone and my thyroid stimulating antibodies. They were so high that it's undeniable they had been there for a while. They did their job and tested my thyroid per the standard of care. I had thyroid eye disease. My eye protruded from my head; it actually pushed out of the socket and was painful. That was the reason they sent me because they bounced me around and they sent me to an allergist. But the eye disease is the only reason that they finally tested me for Graves' disease. It took me two years before I was able to even start thinking about tapering off my medication. I finally got this controlled after a couple years. I was finally at a point where I felt like I can start working through all of this. This was really scary. I already have chemical sensitivity and got this Graves' disease, this could get worse again. So, I decided that I needed to put my life in a position where if anything happens, I'm prepared to deal with it. I moved to the state capital, to our South, to find better paying work because there were just more opportunities there at the time.

I was staying with friends and I got a job with a green cleaning company. The clients understood, and they had a preference for living in a toxin free environment. We were required to use non-toxic things to clean their homes. I was a very physical person, and I still am, but am just trapped in this body. I have tons of energy and am hyperactive and I love the physicality of labor. I love working and challenging myself. It was a thrill to be a thirty-three, thirty-five-year-old woman who was working with women a decade younger. And we were in this neck and neck competition to see who can get their job done faster. It was good-spirited fun, and I was enjoying myself. I was with them for about six months, but then the building that I was staying in with my friends had gas leaks regularly. I can't be certain, but I started having these problems with my left foot and it felt like I had something inside my toes. It felt like bones inside my toes and this was in 2013. I can pin down the dates because the first time it happened was in June. It was my left foot, then it happened to my right foot on Thanksgiving. My hands and fingers clubbed right before Christmas. So, obviously we have some vascular problems. To this day, my doctors will note that there were gas leaks at these times and they are not dismissive. I read my doctor notes, so I know that they're not saying, "You're crazy." They're just noting what I say. It is excruciatingly painful to have these problems, and they diagnosed me with Raynaud's syndrome. That's fine, except it doesn't look like Raynaud's syndrome. The conditions on my hands and feet meant that I can't clean anymore. My fatigue is so bad. It looks like I have mono. They did a series of testing and they tested me for small fiber neuropathy. I'm being retested for other kinds of neuropathies now.

[01:41:01]

In 2013 in December, I went down to the Social Security Office out of absolute helplessness. I didn't know what else I was going to do. So, I thought to myself, I can turn it in, and I can always retract it if I find something else. I had been trying for years to maintain jobs that didn't require me to work with chemicals. I was already so limited. Somewhere in between the weight,

and the treatments that they've given me, and other (environmental) insults over time, I am to a point where I cannot stand or sit too long. If I need to go long distances, I really need to be in a wheelchair. My shoulders and back are so weak. It's like my muscles are made of bubble gum, and they don't hold anything in place.

I'm waiting to talk to genetics to find out if this is a Ehlers-Danlos syndrome or is it Marfan syndrome. It's looking like it's Marfan syndrome. How can this be happening to me? I'm a forty-year-old woman. How do you not know you have this your whole life? Apparently, it can be switched on at any time. I have these hosts of infections from the immune suppression. I didn't know until a few years ago that the gas leaks would cause a problem; malnutrition will cause your immune system to take a nosedive. I have gastroparesis, which means your stomach muscles stops working and you vomit back up everything that you try to eat. So, it is not a surprise that I am malnourished. I know that it's not just a gas leak, it has to be the hydrogen deodorant, hydrogen sulphate and more (inaudible) and propane. I say this about the canary in the coal mine, and it's a perfect example because when I was working at the water damage company, my boss insisted on using these propane heaters to keep the trucks from freezing. I would get so sick every time there was a leak of the propane. One time, I said to one of my bosses, Larry, "There's a propane leak, there's a problem. I'm getting sick. There's a propane tank leaking." He believed me, and went into the depot, and found the propane tank that was leaking and shut it off. No one else could smell or detect it. If I'm getting sick and I can tell you exactly what is making me sick by the reaction that I'm having, this is a very, very real thing. That, and the deodorant and the gas, will cause me to start vomiting and I am fortunate that I'm able to heal up well enough that I can continue to eat solid food usually after a few weeks. Some people end up with feeding tubes from this over time. Everything has just gotten worse and worse and worse. Stairs are impossible for me. I can't go up and down stairs. My joints don't hold themselves in place. By the time I get up there, so many things are in spasm. There is no medication I could take for any of this. I don't get a muscle relaxer or pain reliever because I overdose on everything.

[01:44:09]

VAUGHN: What about muscle testing? Have you tested positive for specific chemicals?

ACEM: I haven't. I have yet to find testing. I have yet to do a lot of the testing that is available. They have urine metabolites for a number of things that they can do with functional medicine testing. It looks at a lot of common toxins like styrene and that type of thing. Some of the things that are of the greatest concern, like trichloroethylene, they don't have a good metabolite test for that. You can go in and do a toxic screen. What they show is like your urine metabolites, for whatever narcotic painkiller, and it should in principle be the same thing for any chemical. They don't have clinic available testing for a lot of that and what they do have is really dumb things. I did a heavy metal testing, and my styrene was really high. I'm trying to remember what else there was, like my stellate concentration was really high. Part of the problem was that a lot of those numbers were too new so it was meaningless. They don't have a lot of markers for other things. So, there hasn't been a great point in testing.

In the instances where a certain thing makes me sick, I have gone to the emergency room. I would tell them that this thing is making me sick, and I would take the thing out of the plastic bag and tell them to measure my heart rate. Sometimes I'll get a doctor at the emergency room who's right on board. He would give me the prescription for the antihistamines and tell me, "Just don't bother filling it." This is the relationship I have with these people. The doctor just knows, and we can measure. I'll also get the PA (physician assistant) at night. She's like, "Well, we can't do that. That's not ethical." It's not ethical for this stuff to exist in the first place, but it does. I'm just here for you to document what's happening. It's three o'clock in the morning on a Tuesday night, and you guys aren't busy. It's the best you can do is note that X product causes X reaction, and try to measure the reaction at that time. It's better than doing a blood test to try to check your formaldehyde exposure because that's the limit of the testing at this point. There's always the ethical questions. There's a doctor in Texas who does the exposure chamber. But the problem is that it's not the most objective testing. It is a very limited range of chemicals, and it's not something that can be used widely in practice. You have farm workers who are exposed to pesticides come in, and you just assume that it's the pesticides; that they're drinking alcohol to numb the symptoms. It's a well understood thing, but nobody is going to spray more pesticides on them to make sure that's the reason. That's not something you do. There's a lot of fine tuning that science and clinical science must go through before we have tests that really mean anything, or that's concerned.

[01:47:50]

VAUGHN: What are some of the kinds of tests that you have been able to receive? You mentioned the first test was for Graves's disease, is that right?

ACEM: Yes. The arterial blood was the first testing that led to the multiple chemical sensitivity diagnosis. I think that kind of testing to measure the effect is really the best that we have right now because you can't fake that. Toxic encephalopathy is a really common diagnosis with all chemical sensitive people. It sounds scary, it's inflammation of the brain. After a point that counts as a traumatic brain injury, and you have to measure it while it's happening. You need a baseline of this person when they're not sick, then you need to know what they are like when they are sick. You need to keep them away from what's making them sick, but measuring those changes in the brain requires a lot of effort and money. It requires a compassionate doctor who's willing to put in the effort. What you're doing is measuring the effects, but what you can't do is measure specifically what thing necessarily triggered symptoms. Doctors aren't trained in occupational medicine; even occupational medicine doctors are only trained so far. The training word is important; they're not educated, they're trained. They're trained to use a flow chart, to think in a certain way and to see a certain set of problems in a certain fashion. They're not trained to think critically after a point. So, the best we have is coordinating care with whoever can measure the effect of the thing. As a patient, what you're telling them is that you were exposed to x substance. Because correlation is not causation, we can just neutrally note that you believe this is what caused it. This is different from them saying, "I believe that you believe," which makes it a psychological problem. Doctors should just accept that what we're saying scientifically and objectively. If I told them I was exposed to a stack of library books, they should just note on paper that what I'm experiencing looks like kidney function and that my

kidney metabolites aren't quite right. They can just leave that on paper. That's what we have right now.

[01:50:22]

VAUGHN: Has that been one of your particular tactics? As you've said, to bring in the substance or the object that you were reacting to? Did you also say that you were trying to work closely with a doctor that you've developed a relationship with who will note that for you?

ACEM: Yes, and sometimes I get lucky, and he's there. Sometimes he's not, but it's just about finding your team. Find your team and just stick with them. A thing that I see other people running into—I don't know how to communicate with them when this is happening, it is terrifying and upsetting. You hit walls so many times, and I'm convinced that a lot of us do develop some kind of post-traumatic stress from being treated as poorly as we are. It's important to not take it personal and keep trying. Be as objective about the whole thing as possible, rather than really getting upset and saying something you don't mean to this doctor that you need. Either he's going to suck, or he's not. But if he's not, you don't want to alienate him. Be as matter of fact, and as objective as possible about this whole thing, and don't go in with forty pages of Google notes. We have to do the homework and have to advocate for ourselves and have to read but you have to reserve the ego of the doctor you're seeing in the office. It's almost like you're doing politics with them, and it is a full time emotionally exhausting job. We should be able to knock something off for medical bills for the emotional labor that goes into dealing with all of it. But that's the only way to get anywhere with them at all. We should also have realistic expectations. Expectations vary by individual and there's people who expect that one day there's going to be a pill that makes us impervious to chemicals. It's like, "Welcome to planet earth; that's not going to happen." There's the people who stomp their feet, and they want the doctors to do something. And what they mean is they want justice, they want this to stop, and they want to not have to live in this world. And unfortunately, that's not going to happen.

So, you need to find and develop your team but maintain realistic expectations in your team and be realistic about yourself. As hard as it is, you have to stay calm and be self-aware. Don't overreact and don't make the situation worse by throwing a tantrum in front of the doctor and telling them that they're wrong, and here's the evidence. We know they're wrong. But throwing forty pages of Google notes that you printed at the library isn't going to help convince them to help you. I think understanding the way that the whole process works is the best way to advocate for yourself. We should also accept that getting a positive outcome of any kind is going to probably take any of us years. It's a long arduous process and science is about observation. If we scientifically observe what's happening to ourselves, you have to test and retest, then you have to study and restudy. You have to confirm your study, and the same thing applies when you're looking at your own reactions. So, I'd suggest to go in and find your team and to tell them to note this because you think it's x. When it comes time for them to evaluate what's happening to you, they have this big, long history of all the things that have happened to you. Over time, they will record the same repeatedly and then the evidence becomes undeniable. There's a lot of learning to validate your own feelings that comes into play. That's why communities are important since all of us validate each other, regardless of what illness you may have, it's just as bad. So, I'd say validate yourself and then find your team medically.

[01:54:40]

VAUGHN: I want to circle back around to community in a moment. Can you tell me the level of self-research that you have had to conduct and participate in? What kinds of tactics and things have you done?

ACEM: Do you mean just in terms of understanding the illness?

VAUGHN: Yes.

ACEM: Okay. It has its own history. It was the drugs, the birth control, and the antidepressant reactions that finally made me start looking at why I'm overdosing on these drugs. I realized that's probably what's happening with these chemicals. Thank God for the internet. For all of the downsides, it's definitely an up because you have access to endless research. You can find out how we metabolize these drugs through certain enzymes. The next step is finding out that mold is the same thing. Eventually I found that multiple chemical sensitivity is a thing. There's a history since the 70s that people are reporting these complaints, and it's a thing that somebody knows about. I found out about Dr. Grace Ziem, in Maryland. I don't remember, I had a phone consultation with her once and then now she doesn't practice anymore. She was showing evidence that there's these metabolic enzymes that are probably processing all of these chemicals. All of us have the propensity to have specific nutrient deficiencies. B12 is another antioxidant precursor in the body, and we're all deficient. So, you learn to take extra B12 and other things to help support your body in the recovery process. That's where it started and finding out that the Gulf War illness was a huge thing too. There's some (NR3C1) and PON1 (Paraoxonase); there's some specific genetics that they found there as well, for Gulf War veterans and their complaints. That research is actually very interesting and informative. We are finding that a lot of us, when we look at our genetic data, we're seeing a propensity in our ability to recover from these injuries and that type of thing. So, that's where it started. I just started by looking at why I was overdosing on this stuff, and then finding that reason.

[01:57:42]

VAUGHN: Who are the medical doctors that have proven the most useful? You mentioned Dr. Ziem in Maryland and one of the ER doctors that has been the most helpful to you.

ACEM: Yes, off the top of my head. Dr Ziem was in functional medicine, and she was on the phone as a consult. The emergency room doctor, and approaching them the right way, has helped somewhat. Functional medicine was good; that entire department is good. It's baseline health. They do a lot of the weird testing that can help you make sure that you're doing all that you can to take care of yourself. If I had to pick one that I would send anybody to, and the people that I have sent anyone to, are to functional medicine. This is because while they don't exactly advocate for chemical sensitivity patients, they are pushing the notion that eliminating the stuff from our lives is important. I really feel like that needs to be our endgame. It's just minimizing the stuff that makes us all sick. If you make it sexy to get rid of perfume, I'm fine with that. It's the problem.

The few chemical sensitivity doctors that are available are prohibitively expensive. Dr. (William) Rea has passed away. Some of the treatment modalities are a bit dubious, and they really do bank on the desperation of people like me that need to keep functioning by any means necessary. So, we latch on to any theory that validates our experiences and promises to make anything better. There is nothing that makes this any better, except avoiding it entirely. Support your body and avoid the toxins, period. That's it. If you can find an environmental illness doctor, that's great. But, honestly, functional medicine is probably your best bet. Not only will they believe you, even if not to the extent that you want, they will at least help you make sure that you're taking care of your body in such a way that you're doing the best you can at the end of the day. You can say to yourself, "I am doing all that so I can (to) be as well as possible." That would be my first go-to besides an emergency room physician.

[02:00:24]

VAUGHN:

What was it like the first time you read or heard about multiple chemical sensitivity?

ACEM: It was like, "Wow." It was less affirming, because I'm less likely to doubt myself anyway. I'm a weird perfectionist; I'm rigorous about my scientific process, even with myself. I feel like I have to justify anything that I'm saying to anyone completely. So, I went through every variable to make sure that I'm as objective as humanly possible and can prove that. So, I found out there are other people like me. On the flip side, it was the beginning of me thinking about being assertive enough. Especially on the internet—there were a few books—But there are also a lot of people on the internet, and they are very frustrated because the doctors don't believe them. This is what we're up against. I'm ready to go to war because this is not acceptable. We must find a way to make this work and be taken seriously. That's been the attitude from the outset: I'm not accepting that you don't accept this. This is real, plain and simple. You can ignore the evidence and I'm going to think you're an idiot if you do, but you can't say that. You have to be realistic. I was pulling out any little tidbit of information that I found that might be useful to experiment or to pass on. For example, dextromethorphan has been found useful. Dextromethorphan has been noted for a few decades for stopping the chemical reaction. It will not stop the damage in your body from the chemicals, but it'll help you get through a situation without looking like a crying, collapsing person that has some mysterious thing that nobody knows about. You can only stop the symptoms. It's the same with tri-seltzer, Alka Seltzer gold; you can take that and it's going to help you for at least this two hour period that you have to survive this environment. There were little tidbits there. I think that was the reason I kept going back to look more, and looking at people's arguments for why this is happening, or why this isn't and reading the science on that. If you just Google scholar the term "multiple chemical sensitivity," fifty percent of what you find is a bunch of studies that are so poorly designed it's guaranteed to make us look like this is all in our head. You won't have the right questions to find the evidence that is affirming what we know is happening. I was just finding a bunch of people who were basically sources of information that I was going to run with.

[02:03:39]

VAUGHN: Have you come across, in your research, studies that you found insulting?

ACEM: Yes, they are insulting. It's posed some challenges in terms of me even interacting with certain members of the community. For example, there's some studies suggesting that the carbon charcoal masks don't do anything for MCS. They don't; they are not designed to obstruct chemicals. The only way to protect yourself from a chemical exposure is to remove yourself. If that means putting on a respirator, then you need one that actually stopped air from coming in, to stop a reaction. The tone of these studies are problematic, they would say that they showed charcoal masks make no difference and nothing is compared to control. So, they recommend cognitive behavioral therapy to these patients, and it's this tiny little group. Nothing is ever exactly replicated because they don't bother repeating it, so it's all very sloppy. But if you're a person who really has a vested interest in not believing that this is real, you're going to go online and grab that, and nobody's going to question it because scientific literacy is lacking in our country. So, you have these fifty papers, and you can frame MCS as "it's all in your head." There's no consensus on that any more than there's any consensus on the other side that this is real. Here's all of the evidence that it is real. There's been a lot of that, where it just seeks to invalidate. There's always that little comment that says the study participants were mostly women. The best you hope to get is the generous suggestion that maybe it's related to hormones, and you take that to mean we're hysterical, not that there's legitimately a connection to the fact that we have estrogen in our bodies. So, there's a lot of that out there. There's a lot.

[02:05:58]

VAUGHN:

Can you tell me how this illness has affected your relationship with your family?

ACEM: Where we are at now is that I mostly don't talk to a lot of my family. My mother's side all have their own disagreements. That was something else entirely. On my dad's side of the family, it is not even a question of whether chemicals are making me sick. It's just a matter of I have health problems. I'm a family scapegoat, as it turns out. They just kind very much minimizing, "Why don't you get with the program and do what you're supposed to do?" They weren't there for literally two decades to see that I did everything I was supposed to do and then some. I don't take it personally, but I also don't talk to them. My mother was very abusive about it. I had to take care of her full time after she broke her leg before she passed away. I went over there and she and my brother would start the laundry with her obnoxious Tide and her ridiculous fabric softener. I would say, "Mom, I can't be here with the scent." So, I started doing her laundry with my tree pulp unscented neutral soap. She'd say, "the clothes stink now." If she didn't smoke, her clothes wouldn't stink. First of all, let's start there. Second of all, it's going to wash out eventually. It was also the first time I became aware of the fact that it's not that things smell, it's that they don't have a good smell. I've been learning along the way that people psychologically associate good smell to clean smells. Smelling nothing means it's dirty. She's very much this person.

There was this back and forth as I'm taking care of her because I refuse to use the poisonous stuff. So, I told her, "Guess what, you expect me to come over here and clean your house, do this and that. So, we're going to do it my way. Because if you expect me to stay here, I can't do that,

and continue to go to my jobs, and take care of you if I am sick all of the time.” It was really interesting, because my mother is a typical example of the way that people are. I said to my youngest brother who was living there, “No, watch. We are going to start the dryer with the poisonous stuff. I’m going to feel sick and start nodding off. Mom is going to start crying.” Ten loads of laundry later, sure enough, every time you start the dryer, my mother starts crying. She was so depressed. She was so in pain. My mother had hyperthyroid and didn’t know it. She had all these problems and refused to go to a doctor. Like a switch, every time I started the dryer and all of these chemicals are heating up, and the vent is blowing it right back into the kitchen six feet from where she’s sitting almost always, she’s crying. But she’s in total adamant denial that this is causing a problem. At this point, we are one hundred percent sure that the dryer fumes were contributing to it. But, she was very abusive and wanted me out of the house. I would go to visit occasionally after she finally recovered. I’d tell her, “Mom, I’m going to stop the dryer while I’m here. I’ll start it again before I leave.” She’d just respond with heavy sighs and nastiness. I had to learn after a point to draw a line because I used to not say anything. I used to go over and endure and expect I was going to be sick. I would pull over in my car and nap for two hours until I felt better. I got tired of doing that. When I thought about how many hours in my life I spent accommodating people with their chemicals, I stopped doing it. She was nasty, and I had another brother who didn’t believe me. He didn’t believe me until he started noticing problems too. Ordinary people who think they’re not getting sick are probably getting sick too. I won’t say supportive, but he will at least check with me. He’d tell me things like, “I had a girl in my car last night and she had perfume on. So, you might not want me to come get you.” It’s a little bit of kindness, but by and large, it’s very unsupportive. My stepdad was a nasty human being about it. He didn’t think it was real and to this day he keeps asking me, “Are you better yet?” I have a multitude of things that will be the potential reason that I die. So, it’s just people are not kind and they don’t understand. In terms of family, I just don’t have family. They’re not accepting, and so my choice is to just not have family.

[02:11:08]

VAUGHN:

Did you say your mother has hyperthyroid or hypothyroid?

ACEM: She was overtly hypothyroid. After menopause, she started developing the most common illustration of hypothyroid. Her menopause happened, the weight gain, and inevitably, a ridiculous percentage of the population ends up hypothyroid after menopause. It can be subclinical. She went from this little waist like I am to a woman who weighed 250 pounds and couldn’t carry her own weight because she was atrophying that badly. She was so hypothyroid that when she finally went to the emergency room, it was because she was paranoid and delusional. She believed that praying mantises were monitoring her conversations and that my stepdad was trying to prostitute her out while filing for divorce. Mentally, there was really something wrong with her. Finally, she said to my stepdad, “I need to go to the hospital.” They admitted her, and the first thing they did was check her thyroid. Her thyroid hormones numbers were so bad that the doctors were in shock that she was alive, that her organs had not shut down. She was very hypo, and was opposite of me. I had been saying to her for years, after learning about thyroid issues, “You ought to go to the doctor and get your thyroid checked.” She’d say, “Don’t diagnose me!”

“Okay, mom. But you cry and you complain. Maybe if you’re crying and complaining, it’s time to go to see a doctor.” She had some pushing signs and some eye changes that did not look dissimilar from what was happening to me. She went and saw one doctor who poked at her eye and told her to take Benadryl and sleep. No wonder my mother didn’t want to go back; she was experiencing dismissal like most of us do. We have an average of six or eight years or something before we get diagnosed because doctors dismiss everything. I was trying to convince her to try again, but she really just wanted to believe that there’s nothing wrong with her. She was hypothyroid.

VAUGHN: Were your brothers also having some kinds of reactions themselves?

ACEM: One of my brothers seems to notice that he itches with certain detergents or certain colognes make him dizzy. Pesticides were a huge thing. For example, the insect repellents. The mosquitoes were really bad the one year. Since I can’t use that stuff, he sprayed it away from me. He was wearing it and said, “I feel like crap now. I think this insect repellent is making me feel like crap.” So, then he begins to search to find the insect repellent that works, and doesn’t also make you sick. The repellents all have that fragrance undertone and whatnot. He’s not as sensitive as I am. He wears some body washes, but he’s mindful of me. He notices and believes that it’s real because he does experience a little bit of that himself.

[02:14:26]

VAUGHN: What kinds of responses did your extended family have towards your chemical sensitivity?

ACEM: I’m closeted about the chemical thing because they think that if you have a disability, you are defective. My disabilities are all big and very real. The attitude that my grandmother had was, “When are you going back to work?” When I can work, I do, but there isn’t much work for me to do given my current situation. I just tell her I am working, and honestly, if I could be all the time, I would be because I’m just that kind of person. I just don’t even discuss it. I pretend everything’s normal because I cannot look at them and think that they’re okay if they’re going to treat me like that given how devastating this all has been for me. I worked many jobs for years just to make ends meet and to save money. I had my retirement plan. I had everything that normal people have, and I lost all of it to being sick and paying for being sick. So, it’s insulting to have them act like I’m just faking it or not trying hard enough. I just don’t even expose myself to that. My toxic social environment is not going to help me be as well as I can be given what it is today. So, I just cut people. It’s not good, but it’s not worth the stress either.

VAUGHN: How have you managed economically, as someone who is as active as you have been, and continue to be?

ACEM: I am currently on disability, which is nominal. It is not enough to live on and it’s actually really very terrifying. When there’s work available, I do it. I’m a patient instructor at our local medical school. My boss is fighting tooth and nail to make sure that they keep the program because of changes in the way that the medical schools work, they feel that we have no purpose.

But when there's any work available, for example, a new person I can train, she lets me participate. It's a little bit of extra money, and it's also good for my mental health. I live on very, very little. People always say, "Oh, you're a system leech." Well, I live on very, very little, but I'm a couple of dollars over the threshold to get any additional assistance. My very nominal check every month has to be stretched down to the penny. I don't get food stamps, I don't get supplemental income, and I am not getting any kind of assistance. I'm forced onto their insurance, which is very limited. I still have to pay my insurance copay every month, and my premium every month, like everyone else. It's required, and I don't have a choice to not have health insurance. That's automatically taken out. I'm well below the poverty line with no assistance. I go to food pantries and whatnot to make sure that I have calories that I can consume, while having a special diet because I have a gluten issue. It is challenging and depressing. But that is literally how I put gas in the car to get to doctor appointments. It is how I afford what very little medication I can take. It is how I managed to afford the couple supplements that I'm supposed to be taking to help mediate being near people. That is my income and it is very small, and it's scary.

[02:19:06]

VAUGHN: Tell me a little bit more about your dietary management?

ACEM: You get really creative when you're broke and you have (to) eat gluten free, let me tell you. There are food programs around the country that have been helping out a little bit because they do have really cheap CSA (community supported agriculture) boxes. Or, they will give away free Farmers Market produce if you show up at this time. So, there's that kind of thing. Every time they've tested me for celiac disease, it's been in the least optimal condition to get a positive result. My GI (gastroenterologist specialist) doctor is telling me, "We're just going to assume that you have it" because I have autoimmune diseases. That's a fair and general assumption that a lot of doctors are making now. When you have a patient with an autoimmune disease, just assume that they need to be gluten free because of the propensity. If you look at a person's genome, it is going to be there. Whether or not it's expressing, gluten is inflammatory and it's causing the tight junctions in the gut to not close the way that it should. So, even if the patients are not celiac, they are not well nourished, and they're blocking nutrition from getting into their body. They can never get well if they're eating the gluten. It's an across the board thing and my doctor said "We're just going to say that you have gluten intolerance. Just stay away from it. Don't even do it." Because I kept ending up anemic or I have muscle weakness, which is worse. My thyroid completely spirals out of control if I start eating gluten and my allergies get worse. It's clearly having an effect and it's clear, at this point, to my doctors that there is a cause and effect that is making everything worse. There's lots of illnesses and lots of unknowns. They are just finding a way to make sure that you're eating the way that you should be without backsliding into spaghetti basically.

VAUGHN: So, you are especially careful about a gluten free diet?

ACEM: Yes. We have a farmers market and they throw tons of produce out the back door, so I literally go in the trash. There are a number of us that show up on a fairly regular basis to go pick through the trash because it's perfectly good produce that they're throwing out, and it's also free.

You do what you have to do to ensure that you're eating the bare minimum that you're supposed to because everything would be so much worse. I could realistically become a woman in the desert, pushing a shopping cart around, and could hide under my tarp at night. But I would still have to eat that way if I wanted to be able to ever push my cart to go get water. If I didn't have a car, I would be dead. I'm not even going lie to you. It's just that simple at this point. If trash picking is what you have to do to get your diet, then that's what you do. Because it is that real that the gluten is causing a problem.

[02:22:18]

VAUGHN: Have you met other people who are experiencing similar things? Do you feel like you have a community or a network?

ACEM: I've met a lot of people, more of them online than physically, for a lot of reasons. I require a lot of heat to be okay. But for a lot of people, it's more common to be heat intolerant. So, these other women that might be out in the desert have these sensitivities as well. They're all in Washington and would say that it's moldy here. They might go down there, but it's too hot in Arizona, which is where I need to be. There are a few women locally that I've met online. We threatened to meet up, but I'm always hesitant. They'll invite me to go to this coffee shop. But I'd say, "Oh yeah, I don't know if I can handle the perfume near that coffee shop." But my housemates all smoke, and you wouldn't be able to handle the smoke. I'm hesitant to even send gifts to other canaries because I'm afraid of what might happen. If the postal carrier is wearing cologne that day, they're going to get sick. So, it's nice in theory to connect, but in practice may not work. So, I don't have a lot of the actual physical network.

My boss is a breast cancer survivor, and the chemo made her somewhat chemical sensitive. She's not as sensitive as I am, but she'd say, "Oh, you might want to stay away from that because this is really getting to me." She chased me out of the office a few weeks back because they were installing flooring in the lunchroom. I thought it'll be okay, until it wasn't. She said she was going to have a headache when it's done. She knew it was going to be much more than a headache for me. I can go to her house and have brunch once in a blue moon. So, there's a little bit of community, but it's not that I can get into a housing situation with this person that I can rely on to be a safe roommate. And that goes in reverse, I use Tom's unscented deodorant, but for some people that might actually be too much. We need to have independent housing so that everybody's unique needs can be somewhat accommodated. I can tolerate driving a car, and other people can't drive regular cars. Some people have a diesel RV (recreational vehicle), but I can't be anywhere near diesel. So, there's a lot of conflicting sensitivities that serve as a barrier to anybody being able to meet up.

VAUGHN: Earlier in the interview, you talked about emergency food and scavenging perfectly good produce. Do you feel that this is a tactic that other people who are experiencing these kinds of illnesses are utilizing as well?

ACEM: Yes, that's how I learned about them. I knew of other people that have had to do very similar things. There's one guy in Arizona, who told us that the CSAs in Arizona are cheap and that some of the charities give away produce for free. We were able to get a reasonable amount

of vegetables for forty dollars a month. He's out on disability for a multitude of work injuries. How do you even function? He'd say, "I don't know what I would do if I had a bunch of kids" and that type of thing. He's very disabled and these are the kinds of things (scavenging) he goes out for. There's a couple of markets or produce stands, where they leave a bunch of the nuts and nice looking stuff to just rot on the earth. He would swing by and grab it. Over time, I've known people in Cleveland who are just going through a hard time. Unfortunately, we have a really bad problem with the narcotics here. If you listen, when you're in the emergency room, you learn a lot from these people who dumpster dive. They full on dumpster dive, or they go to the market after it's closed. I've also known people, who are not friends but are casual acquaintances who would go shopping after the market closes. You show up and there's these other people. My leg is broken, and I have this back problem and this brain tumor, and I can't work for the next three months. Well, this is what you're going to do. Food stamps were cut. So, people are having a harder time eating, period. Let alone (eating) well. So, it's whoever. You just grab onto any suggestion you hear from anybody who has a similar situation to you.

[02:27:19]

VAUGHN: In your pre-interview questions, you mentioned that newer people to the movement don't understand that some have been around for long enough to know that people have disappeared. Are you referring to suicide, would you tell me more about that?

ACEM: Actually, there was another suicide in the community and it was really devastating. One woman's husband in the group died. I think he might have been a pentobarbital suicide. You can go across the border and get pharmacy grade pentobarbital and euthanize yourself. He's gone. It used to be a regular thing before everybody was on Facebook. There were online forums, you could join and talk to people. Some forums were specific to chemical sensitivities and some of it was physical, like snail mail. You get the newsletter, and they will publish pieces to say "We're mourning the death of so and so this month." They finally gave in. You hit a point where—I have a lot wrong with me, and it's frustrating that some members of the community can be—I have an endless amount of patience, at the end of the day, with all of it. Not only are you ... sick from the chemicals, and it's affecting you in a neurologic way, but I don't know of a disease that takes away your hope, like chemical sensitivity. I have mostly invisible illnesses and at least I have something that when you Google it, it is portrayed as real. There's nobody, or fewer people, are arguing about chemical sensitivity.

I have a disease specialist for chemical sensitivity. My friends can say, "Oh your thyroid's bad. I totally understand." Or, "You're not able to walk today because your joints won't stay in place. I understand. Do you want me to push you around?" I don't ask for that because I get motion sickness and they understand. My friends are understanding, but people in general are not understanding. They think you just don't want to go to the grocery store, or have to take care of yourself. You just want to be miserable, you don't want to try, you don't want to just live in a house. All we want are the same normal things. At this point, I think we want it more than anyone else. We try to embrace the unconventional living and the weird things that we have to do just to get by. But what happens when you have seven other disabilities, and you no longer can run or escape anymore? You can't advocate for yourself anymore, because you can't swallow, let alone talk. It is the one thing that absolutely removes all hope for all of us after a

point. There is no safe space, there's only the space that is the least bad for any given person at any given time. After a point, all of us are so exhausted. When Alexandra contacted me, I was to that point. I'm more okay with it. It has been to a point where realistically I may not be able to do life a lot longer. And, I'm not suicidal but what else am I going to do. I can't be the woman pushing the shopping cart, because I can't push the shopping cart. It gets that dark.

[02:31:55]

I'm just so excited to have an opportunity to say something in a way that people would hear it. Hopefully then, they'll know they are not alone. Yes, it can get that dark and scary. These are things that we know and maybe that'll help you get what you need. It's just an opportunity to say any of that. I was that desperate to have something that made me feel like I had a sense of purpose and was doing some good because there is so little that you can do after a point. When you can't even have a hobby when you can't knit or crochet because you can't keep yarn, or because you can't touch yarn. Or you can't paint because there are no safe paints anymore. Or you have no home. What do you do for your mental wellbeing? You get to a point that is desperate and lonely and isolated. In that respect, it simply does not compare to any physical disability that I am aware of. Even people with mental illnesses, schizophrenia, depression, anxiety, with all these celebrities coming out with being bipolar, there's at least more coverage. That still has its stigma, but it has less of a stigma than being a human canary. They still have options. These are people who have mental illnesses; they're not people who can't talk about it and have no access at all.

There's a fight over accessible spaces. I'm acutely aware of how many places are not accessible at all. They're not disability friendly because they don't have a ramp. I wanted to go visit this little tiny art museum that appeared safe, but I couldn't get up the stairs, . It's not accessible, and it's really crummy for people who are dependent on mobility devices. They can't get into these places. But at the end of it, if I did manage to get into the building though, there was no guarantee I would have stayed because of the chemical sensitivity. On top of not being sure that I wouldn't get sick, there's the humiliation of telling people that I have to leave because of X. Or lying about not feeling well to leave and denying my own personhood. All of that is me making light of the fact that this is the best that I have left for the rest of my life. I'm trying to make the best of what is, and what is, is so little. If I had any less, I would have absolutely nothing. What is the point? I'm not the only person who has been here. There have been a lot of people before me who have spent everything they had, and borrowed and spent more to try to make a situation livable and workable, according to a modern standard where everybody has a home and is not homeless, which is like the worst thing on earth, where you are fed and not sick all the time because it's just this toxic black sludge to be this kind of sick all the time. You give up when you have zero quality of life. Medicine doesn't treat people and the capitalist society will not accommodate us at all.

[02:35:14]

It is the worst disease and illness to have in my opinion. Even when there is access, there's no job accommodation. Once your health begins to deteriorate because of chemical sensitivity, then you're completely out of options. It won't give you any hope at all. What's the point being here?

It's very common to find out that somebody gassed themselves, or they went and shot their brain out. There's been a lot of suicides over the last how many decades, and it's always canaries who are completely isolated and have literally no other option and nowhere else to turn. We're tired of having nowhere else to turn. Over the last not quite twenty years, since I started, there's probably been a few hundred people that I've heard of (that committed suicide). These are people I have interacted with personally or have talked and exchanged letters or emails over time. If that's what I know of, imagine how many people I don't even know of. These newer people have no concept. They're fighting the doctors, and they're going to get their diazepam, and their allergy medications for their mast cell activation. This lab work can be shown to anyone to get job accommodation, while they're very sick. They have these problems and don't understand what it's like to be a person who has to fight even harder to get any acknowledgement on paper in any kind. They really have nothing that's as tangible to show people that this is real to get any kind of accommodation or validation. There is no medication you can take. Supplements are nice and does help but they're not a fix. They're not a Band-Aid that stops you from bleeding. The community is diluted by these people who have no sense of what it's like to literally not be able to breathe the air at all. It gets this dark when you can't, so it can be emotionally taxing, but it is what it is.

[02:37:58]

VAUGHN: Can you describe the kinds of financial burdens that you've been grappling with? What are some ways that you mediate and self-advocate for accommodations? You mentioned supplements, but that's one thing. What are some of those bigger financial burdens?

ACEM: Do you mean for any individual with chemical sensitivity?

VAUGHN: Yes, what are some you know of in your experience?

ACEM: It can start anywhere. There are people who need a mattress and they just spent four thousand dollars this year on mattresses. I've already conceded that you just don't need a mattress. You go with blankets that you made yourself and you roll it up and make a mattress. That's all you can do and that's living in a home with the bed frame. You fight for years to try to stay normal. A bottle of shampoo that is safe for me, may not be able to be safe for someone else, but the shampoo starts at ten dollars a month. You have to wash your hair repeatedly because if you're exposed to anything, it's in your hair. If you don't want to be sick all the time, you have to wash it out. You're paying the water bill, which costs more. Decontamination is a huge expense. Most of us can't use laundromats for laundry. One way or another, we're paying extra money to make a laundromat work somehow. Or spending a fortune on a water bill at home to decontaminate. It can take two to three washes to get other people's perfume out of your polyester t-shirts. There's also the cost of buying replacements for clothing that you've lost because of contamination. Cars are another huge issue. How much money do we all spend on cars? Some people would ask if we think the vehicles are safe, but you can't ask us what we think. You have to go try it to see if it's safe or not. Now you need to figure out how you are going to live for three months now that you got your new car; you have to wait for it off gas because you have to get that off, but it takes years. A lot of people will make a lot of financial mistakes learning to live with chemical sensitivity because you can't go to a store and buy a

book. A lot of us can't go to the store and buy a book; we just wasted twenty-five dollars because that book is making us sick, but we didn't realize it until we got home. Nothing else at home is making us sick except the new book. You go through a lot of money, and a lot of expense beyond just the medical bills, while you learn how sick everything is making you. I threw it out, I had to donate it, I had to this, that, or the other—I have to replace things if I get reactions to them. Once you might feel well for two days—you were just on vacation for two days—but you come home and something in your house is making you sick. You realize it was your tennis shoes. You didn't notice it before because you weren't away from it to know that it was doing it. So, now you've got to find shoes. Fundamental things like underwear and shoes can be really challenging to come by. The trial and error alone will kill you financially.

[02:41:35]

VAUGHN: Can you talk a little bit more about those products without ingredients that can cause greater problems for you? What kinds of products have worked for you? What products had been the most viable for you?

ACEM: Yes, I have been lucky so far. I still use Jason brand unscented products, which have been okay for me. I don't know that everyone would be okay with it. For me, it's been okay. The Kiss My Face company went out of business, and that was devastating because they actually had a toothpaste with Aloe vera that worked well and it was safe, but they went out of business. So, I'm trying this stuff from Whole Foods now. It's hard to find products without essential oils in it; it's actually really, really hard to find toothpaste without peppermint oil and that type of thing in it. I'm trying to remember, but I think it was the Whole Earth brand; I think was the toothpaste that I found that seemed to work okay. I use Jason's unscented soap. I tried an organic all plain olive bar soap that I found somewhere and it isn't great, but it's what I've got. It's amazing how little you use. Everybody's always looking for lotions, but I like olive oil or Jojoba oil because there's no lotion that you can use. People are always trying to figure out how to paint their toenails. I think you should just accept that you're just not going to paint your toenails. The hair dye discussion gets very frustrating. As much as I would love to have my ashy brown covered up, you can't. There is no substitute for hair dye. I was using the hair chalks on a friend's kids and those seem to be okay temporarily. But it's not a permanent solution; it's chalk. Unfortunately, I don't have a lot to recommend in that way. There's a brand, not Every day Shea, but the other one. What was the other one? Alaffia makes a shea-based product line that is pretty innocuous in terms of chemicals. A lot of people find that they have an allergy to latex, so sometimes that can be an issue even if it's unscented, safe, and sustainably produced. So, I like to give my money where it makes sense. That's a good product if you're not allergic to shea. For cleaning, I use baking soda and peroxide. I don't even have great cleaning products to recommend to anyone. I use all natural products like vinegar or peroxide. For kitchen cleaning, you boil vinegar with a pot on the stove, like great grandma did. I use Tom's unscented deodorant, but I don't think everyone can tolerate that. Some people don't like to use the mineral, which is the other option. Those are the few that I can use that are readily available to anybody I think.

[02:45:23]

VAUGHN: You mentioned underwear and clothing earlier. What kinds of fibers or companies do you prefer when you are looking for these products?

ACEM: Yes, I don't have the luxury of affording products made by companies, so I get hand me downs. I wash them intensely and they are already off gassed. I cannot sew like I used to, but I can refit and refashion clothing that I find tolerable and that has been off gassed. I can't say that any company is a great company to buy clothes from or even towels or bathrobes from because it's not something I can afford to do. So, people give me a bag of clothes that they saved for me that they put through the washer just plain with vinegar, and then it's up to me to wash three more times if I want to try to save them. Unfortunately, that's where I'm at.

VAUGHN: Can you tell me a little more about your activism and advocacies? When was the first time when you learned that there was a movement or an activism around your illness?

ACEM: It was later than mid-90s, it was probably the early 2000s. There was a newsletter somewhere floating around and I learned about a community. That community entirely disappeared for a while, actually. I couldn't find anyone and they stopped sending out the Chemical Action Network newsletter. They might be online still; I'm not sure. There was flagging for a while, but it just disappeared, and there wasn't any activism. Social media has been interesting because people like (inaudible) and they don't organize well. It's less that there's a movement and an organized effort. Right now, I feel like everybody always wants the organized effort, but it's so hard to push. It's a lot more about information sharing. At this point, there's a lot of people who are literally just passing around the flyer, or the notices from the CDC (Center for Disease Control) that say the CDC work facilities are all fragrance-free workplaces.

If the CDC is telling us that they have fragrance-free work environments, it's because fragrance is bad. Maybe we ought to have that everywhere else. At this point, unless it's about helping an individual talk to a doctor about what's happening to try to get them help with any component of their illness, it's more about information sharing and learning. The one group that I'm in, we are determined to be science focused. We are not people who are talking about dynamic neural retraining systems. This is not anxiety and it's real. It is an immune reaction and not an anxiety attack. We're not going to pretend and waste our time discussing that. We're passing around as much useful information as humanly possible so that we have a uniform data sheet. You can take this data sheet to your doctor to test for certain allergies. What would be the next step in the process? The next step is to say, "I know that I'm not allergic to these things" but I need to eliminate that as a possibility so when I can see an environmental illness doctor—we can try to find ways to passively shape the standard of care in a way. If we're not going to just treat this as though it's an illness unto itself it becomes part of the normal daily dialogue. It'll just sneak into the conversation. Does that make sense? What do you mean you don't know about multiple chemical sensitivity? A whole bunch of us have it, so we can have it be something that's part of the normal discussion so that there's no more stigma attached to it.

[02:50:06]

The end game would be to have it so that the insurance companies are going to understand that we shouldn't have people using scented body products because it's costing us millions of dollars

and illness in the long run. The FDA (Food and Drug Administration) doesn't regulate anything and the EPA isn't really going to protect us. These substances that are proven safe for middle age, healthy, white males are not proven safe on infants or women. It's not so much organize; most of us just want to share information to shape the narrative in a way that makes things suck less one day. Because of the way that things are organized now we can sign all of the petitions in the world, but it doesn't mean that any politician is going to care about us enough to make sure that we all have isolated safe housing, let alone isolated, safe co-housing. We're running into examples with the legalization of marijuana everywhere. One of the biggest barriers for me in housing right now is legal medical marijuana since I can't tolerate being near it. If marijuana is legal, those of us with mobile housing and accommodation can't tolerate it. It's more than just we're looking to have a massive petition to get people to do any one thing, it's about it being a conscious part of normal medical conversation.

This conversation should be as commonly understood and accepted as cancer is. There's going to be the social stigma, because you're a sick person, but it's a normal thing that happens to people every day. It can be prevented, and avoided. Then we can realistically accept the limits to what this person can and can't do going forward. I'm just hoping that this will bleed over into discussions. For example, "I don't want to go to dinner wearing a ton of cologne because I don't want my friends to not be able to come to dinner." I think it's important to normalize it socially because it seems like any effort that anyone's put into doing an organized project just degrades at this point. Everybody wants everybody else to solve the problem and come up with a solution, but everybody can only do so much in terms of putting forth effort to really do something themselves. A lot of us end up in a difficult position. Where am I supposed to put together flyers or go to conferences or spend eight hours at the EEOC office to find out why and how does the system work? We're not getting the accommodations that we need and some of us are so sick that we can't. So, there's only so much that we can do. It seems like the most practical way to handle it is to just normalize it already. We should just make it a thing that people expect, like pregnancy. Some people have that, and then some people have chemical sensitivity. In both cases, neither of us should be exposed to heavy fragrances.

[02:53:57]

VAUGHN: Do you consider yourself an activist?

ACEM: Yes, sometimes I'm more passive than I want to be. In other cases, I think the way that I do activism has had to change. I don't have the energy that I used to. I went to the Million Woman March in Washington, whatever year that was, and I was one of those people who marched and showed up. I was there and was a voice, an ally, but it has to be more than that. I'm physically not capable of doing a great deal of organizing anymore. What can I do to help any individual advocate for themselves? There are more of us doing that and doing it well. You can hope that the good spreads like a disease just like the bad does. Ideally, we're working to get a web page up where people will have information that they can pull and take to the doctor to ask them. They can arrive in the doctor's office understanding all of these things and ask questions. This is how to have a dialogue with your doctor where you can present to them this information and educate them. There's rhetoric training at Planned Parenthood. What patients need is rhetoric training too. Any advocacy work needs to have its own rhetoric and approach that is appropriate

and that we know will help achieve the ends we're trying to get to. I think that's where we're at with this web page, we are trying to find a way to be more aware and force this to be part of the normal conversation. That's the extent of what I can do for advocacy at this point because I'm not able to organize larger, bigger, and more. These are the facts as we have them, and this is the best way to communicate to get what you need, and it's going to be small. I wouldn't even know how to begin changing disability policies in light of the current political climate. I'm an advocate, but what else is there that we can do? What else is there?

VAUGHN: Have you ever expressly protested related to chemical injury?

ACEM: I have not. There hasn't really been an opportunity. I have not found opportunities to do so, at least where I'm at, and where I have been. I've never even heard of public protests of any kind and part of it is because of shame. There's a lot of people I know that simply wouldn't attend because they don't want to have a spotlight on them. I have not because I don't think there's even been an opportunity that I can recall.

[02:57:20]

VAUGHN: What about the level of commitment to research and self-advocacy that you've described today? You talked about being a patient advocate, and there's so many other layers of work, knowledge, and skill building. Is there any particular achievement that you are especially proud of?

ACEM: As far as I'm concerned, I'm still alive. It's not me personally; I think people need to know that they have to hang in there. They need to know that their feelings aren't wrong, but to stay calm and rational. You start to see progress in small ways. Personally, I've tried so hard and it is a miracle that I have gotten this far. I'm proud of the fact that I've gotten my doctors to a point where they will at least acknowledge that chemical sensitivity is real. That was work on both of our parts. Doctors who I've worked with are open to the experience of other people and are not so closed off. There's a group of doctors that we have, Dr. Ziem, Dr. (Ann) Campbell, and all of these other doctors that were really genuinely pushing for all of us. They were there, treated us for nutrient deficiencies, and wrote letters and sent us to places with appropriate testing when and where we could. They ended up having discussions years ago. Dr. Nosh actually still practices, and she is chemically sensitive. She was at a conference at the Cleveland Clinic before they had finalized the plans for their functional medicine department, so she was part of the process of creating awareness there. I know she puts out surveys now and again. She definitely listens to her patients.

It's about putting in a dent and people just need to keep saying something. I made the phone calls, and talked to these doctors. I told them what my experience was, and talked with and for other people to doctors. You have to keep sharing the story and assume that people are going to take you seriously because this is a serious thing. Eventually the tide of medicine is going to change a little bit because it already has. Dr. (Mark) Hyman, Dr. Walls, and Dr. Lynch, all of them are telling you that toxins are bad for you. They're bad for all of us. I'm hoping that trend continues. While it is not adequate, it's the kind of thing that we need to have. All of that is there because these doctors who are pioneers in functional medicine were there for chemically

sensitive people. They were at conferences that helped shape functional medicine, which in turn is shaping medical care.

All of us have put in so much work and have done so much work to survive. It's starting to make a little bit of a difference here and there. It's really common to see an Instagram post from so-and-so about how toxins are really bad for you. Or suggestions of products that will help detox Bisphenol A from your body. There are things we can do and it's becoming more and more of a normal conversation. Everybody who has put in effort, in any way, is partially responsible for that. It's going to take all of us doing little things every day to make a difference, and everybody has. We're getting somewhere as a team, it's just not happening fast enough. The next step will be housing. I can't say I'm proud because we haven't gotten that far yet.

[03:01:59]

VAUGHN: Can you describe to me ideal housing accommodations that you can imagine? What would it be like given your experience and your friends' and community's experience?

ACEM: We need it to be legal for people to just live. There's a lot of people like me out there. There's a lot of people out there in the desert living in their vehicles or urban camping because they have to go to work every day, but they are canaries, so they have to live in their car. You can't do that in Ohio or New England; it's illegal here. It should be legal for us to do something that allows us to function. Living in a car is not ideal, but it is definitely a start. We need it to be legal for a municipality to allow people to build safe housing without having to install gas lines. It has to be cordoned off from airports because we can't live near airports or military bases. We need it to be legal to test water quality so we know if we're drinking from a water faucet that is safe. There's so much of what we need that isn't even legal because the interest of local municipalities is protected over ours. Ideally, all of us would end up in housing with fresh air and clean water with a variation of solar power and wind. There's plenty of available natural resources besides petrol and fracking.

If you look at a physical map of the United States, the physical space that we actually have to even create a place like that is impossible. Let's say we have \$40 million to create this canary haven. It has to be 250 miles outside of a fracking site and away from mining by several hundred miles and away from contaminated river water. There's literally not enough space. My personal ideal is to win the lottery and have just enough money to be able to go build a cabin in mountain with air so it's safe to breathe. Hopefully, some other people can come share the piece of land with me. That would be ideal, but that's dependent on me winning the lottery. That might not be everyone's ideal, so we're going to have in-fighting because one prefers treated pine and the other prefers Formica countertop because of different triggers. The ideal is to have a clean environment where people go back to where we were several hundred years ago. The world wasn't so sick to begin with. It would be to rewrite history. The end game depends entirely on the environment not getting any worse than what it is. We need the EPA to protect us (the canary community) to not to be smaller and smaller. We need HUD (Department of Housing and Urban Development) to be funded so that those of us who qualify for—Pardon me

VAUGHN: I didn't say anything.

ACEM: Okay. We need to be funded since HUD funding was cut. We need people who are eligible for Housing Choice vouchers to be able to even use them. The money's being cut, so everything we had is being taken away. The ideal is getting further and further out of reach. The ideal is simply a clean house built out of natural elements that is fueled by natural means and not toxic ones. You just make the rest work. A place that you can hand wash your laundry in safe soap. It's that simple for most of us, but work life doesn't allow us to do that, even if it is possible.

[03:06:44]

VAUGHN: What have been your best strategies for minimizing chemical exposures?

ACEM: Sleeping in my car.

VAUGHN: Sleeping in your car?

ACEM: Yes, I've been sleeping in my car on and off for a decade. It's not what I want to do. It's just the safest thing to do. It's been the best thing that I can do. It's been extremely difficult, because the city really hates the homeless, so there's always the threat of police showing up and knocking on the window. There might be jail time or tickets, but sleeping in my car is the single best thing that I've been able to do to manage my health.

VAUGHN: What is the cost of tickets and the length of jail time?

ACEM: Fortunately, I haven't had to deal with much of that; when I'm told to move on, I do. When it's wintertime, it's just too cold. I'm just sick all the time. I go in, and I'm sick all the time. For a long time, I would hide where I could get air. This past winter I was out in the middle of the desert, and there were free places for mingling. I felt better than I have in years. I'm not necessarily more functional, but I felt better than I had in years. Unfortunately, just being able to breathe air that isn't poisonous is the ideal.

VAUGHN: In your pre interview questions, you wrote that you spent time in California and Arizona. Can you tell me more about your travels? Was it particularly guided by your need for warmer temperatures? What was the catalyst for those travels?

ACEM: Warmer weather does me better, and here in Cleveland, climate change is real. I met people in Tucson and they said, "No matter what side of the political fence you're on, climate change is real." Yes, it is. It is cold here. We don't really get real summer here. Two weeks ago, everybody was complaining about ninety degrees. There's air conditioning everywhere, and I can't cope. I physically can't tolerate it, so I have to spend my winter in the desert for warmth. I was in the Colorado River Valley, right along the California Arizona border, going up to Nevada a little bit. Winter Haven is one of the nicest spots and it's warm all winter long. This winter, it was extraordinarily cold there and was very hard until about mid-March. That was the catalyst to move, so that I could just stay warm because of the cold air's effect on me. The indoor air quality

is absolutely horrible. It costs a lot to heat the house, so I'm either sick all the time or freezing all the time. I just couldn't take it. It took me literally two weeks to drive out there because I had such trouble driving, but I drove it. I slept in the desert, and it finally warmed in March and I felt human for the first time in many, many years. So, that's the plan until something else happens.

[03:10:29]

VAUGHN: Were you still living in the car and focused on a particular place in terms of climate at the time?

ACEM: Yes, I was in that area, it was just warm enough. You'd have to avoid the Air Force bases. I tried to find little areas where I'm away from farmland and pesticides. It's not necessarily ideal for everyone. I was just by myself, and I don't have kids or people traveling with me or anything. So, I found somewhere to breathe safely and be warm enough to sleep. It just happened to be there because it is the warmest place in the country in the winter.

VAUGHN: What's your experience of the impact that chemical exposures have had on you regarding your recovery time? Has that changed over the years?

ACEM: There's a couple of factors that have influenced that. I use low dose naltrexone and it is an immune modulator. It just coincidentally happened to take an edge off the intensity of my reactions because it's an anti inflammatory. It's innocuous compared to Motrin and that type of thing. Total avoidance (is the best policy). The more you can avoid, the more easily you'll be able to tolerate hits in the future. By hits, I don't mean going to work for 40 hours a week. I mean, you went to the grocery store and you got sick from the detergent section. But at least you know tomorrow you'll feel better rather than being in an endless cycle that you can't escape. It's like your body is a horrible prison, so total avoidance has been absolutely crucial. The more you can avoid, the more you'll be able to tolerate minor incidents going forward.

VAUGHN: What about this illness has affected your life the utmost?

ACEM: Absolutely no part of my life hasn't been touched by this illness. Because I work, work has been the most devastating. Housing is a huge problem, but I've worked homeless and, you just make it work somehow. It's hard. But being so sick from doing your job, or having to go find another job, and then a different job, and then a third job just to afford living. Work has been the biggest thing, between the job, the work environment, the building, and the people around you who makes the building sicker, there's no place you can go even as a consumer. I don't know why anyone thinks that we can just go out and find a job with this. You can't enjoy a movie, and going to the grocery store is torture. How are we supposed to work in a grocery store or a movie theater? There's no reason to think that it's any better in professional jobs. Everything from the desks to the carpeting to the lack of ventilation in the building makes your work environment a problem. If you can't go out and do things, how are you going to do the things you're asked to do? People always mix up how mental incentive works, they just think "You just don't want to have to go to work." No, I would love to be able to go to the grocery store, but I can't. That's an afterthought to people. But, I need to work to buy soap nuts online. I need to work to be able to

build a piece of anything on a piece of property. I need money to buy the lobbyists so that all of us don't have to do this anymore. I have to go to work. For me, it's work, it's your health care.

[03:14:55]

VAUGHN: How would you say views towards your illness have changed over time? What are the most stunning ways in which they have changed?

ACEM:

Do you mean in terms of other people's reaction to it?

VAUGHN:

Yes.

ACEM: It hasn't changed. What's changed is me, and what I'm willing to put up with. That's been the biggest thing. I have a zero—My grandma's going to pass soon. She's old, and besides my one brother, she's the last of the family that I really talk to. I can't take her seriously. I'm sorry, I don't have time for somebody who wants to treat me like that. So, it's going to be minimum exposure. I don't tolerate doctors who don't take me seriously. When I have an occupational medicine doctor who can look me in the face and say, "I was going to recommend you take this drug, but that drug is a chemical." If that man has enough sense to say that to me and take me seriously, I have absolutely zero reason to tolerate any less from any of my other doctors; that's a medical scientist saying that to me. I have a zero tolerance policy. It has more to do with how I've changed than anyone else. There's more and more people who are noticing that they have allergies, and they're noticing that they get migraines from x, y, and z. I know just as many people who are asking, "Do I get migraine headaches from my deodorant? But I really like my deodorant, and I don't want to smell." You can take another shower; these folks don't want to change, and have no incentive to change. So, I very selectively engage. My life has been cleaned out and I have a zero-tolerance policy for people who don't want to respect the fact that some of us are not able. It's just that simple. It's my own attitudes about ableism and being ableist on myself in what I will and will not tolerate that has changed more than anything.

[03:17:11]

VAUGHN:

What are some steps that you believe could change relationships that people have with this culture of chemicals and artificial tastes and smells? You mentioned these associations that we make culturally with these things and the difference between people identifying something as clean or dirty. What are some steps that might help interrupt or change that?

ACEM:

I keep focusing on the medical science and medical acceptance. Part of the reason that I do that is because I think we are more likely to get somewhere if we treat this as though it's an everyday problem with doctors. We're more likely to get somewhere with that rather than trying to convince people who use Axe body spray and worship the Kardashians to change anything. The corporations that are allowed to make the products that are making us sick need to be addressed.

People need to stop spending the money so companies will stop making products. What people spend their money on has everything to do with any reading. We're not going to get people who wear Axe body spray and love the Kardashians to change that. We are just not. When Febreze first came out, it was unscented and it worked very, very well. People loved the product, but it wasn't selling enough. What they found was that people want fragrance to make them think psychologically, "I'm done cleaning." People want their fragrance. So, focusing on making it a normal part of medical conversation becomes a bigger thing. Doctors who are telling us to eat apples because it's good for us, they can start telling people to stop spraying pesticides because of endometriosis. There is a definitive causal link between a lot of these endocrine disruptors and things like endometriosis. The evidence increases when your doctor tells you that it's bad. The same people who follow whoever on Twitter who are wearing these toxic products because they have to look and smell a certain way, when their doctor starts telling them that they need to modify their behavior because it's making them sick, that's when it's going to start making a difference. So, it's just picking the right battles.

[03:20:13]

We are not going to convince so many people to change their values. All of those values are so tied up in things that far exceed the smell of perfume. Capitalism has to go. We tried capitalism, and it didn't work out. Let's try something else. I was having a discussion with some people that seemed to be really well informed about nuclear energy recently. One of them is a biologist and we were hanging out with other scientists talking about virtues and nuclear energy. I asked him why they were fighting for solutions to the problems of nuclear energy. They said, "We're going to end up in a bubble. Humanity is going to end up in a bubble." I told them, "You got me sold. But you also have to sell me on the solutions." So, we had this back and forth.

In the end, I said, "If we keep poisoning the environment that we have, even if we have a bubble, that is powered by nuclear energy, you still have contaminated water and air outside the bubble. What you have inside the bubble is a bunch of people making each other sick because we're all wearing poison so that we don't have to smell each other's body odor. We're smelling the poison instead. We still have massive health care costs and health issues. Everything is an environmentally triggered illness. We have all of these problems, and we're inside a nuclear-powered bubble." They said, "You just want to go back to the days of Amish and to being a caveman." I said, "Yes, actually, I do." This was like the most offensive thing to them. All of this is part of these modern values that have to do with our economy and economic landscape. How we look at money, and what we value, and all of that relates to capitalism. This just needs to go away. Let's just get an eraser. It's horrible. That's really what it comes down to.

[03:22:48] (End of Session 1 recording)

Interview of Jane Acem

Session 2 (5/31/2020)

[00:00:00.00]

ACEM: That (capitalism) needs to go because it is the core of the problem. People's values are so tied up, so we do this out of habit. Nobody's going to give up the habit and be the person who risks being isolated while change is happening.

VAUGHN: Is there anything else that you want to make sure that we touch on today that we haven't had a chance to discuss?

ACEM: Not that I can think of. I just want everybody to hang in there. It's good slow. I am forty-two years old, and there have been people complaining about this illness longer than I have been alive. We have not come far enough, and science is very slow. Changing the standard of care is very slow, and we're fighting a lot. We can protest Monsanto all we want to, but there's a lot more than just Monsanto that has to be protested.

Just hang in there. I think it's important that we find ways to just keep validating each other's experience. It's the only thing—just hang in there. It's been a long one. I'm forty-two years old, and I'm not going to be getting any younger. With these illnesses, who knows how long I'll live? Everybody just needs to hang in. It's all we can do. I got nothing. Unfortunately, I hate that I feel like there isn't enough that we can do. But everybody needs to hang in there. The only thing I worry about is everybody needs to hang in because we've all got too many other problems that make life too difficult. Just don't let this be one of the problems that gets you too discouraged.

[00:02:06]

VAUGHN: This has been a tremendous amount of time and energy that you have gifted us today. Thank you so much.

ACEM: Yes, hopefully it's something that's useful.

VAUGHN: Yes, this is an ongoing program and project here, and it is multifaceted. This collection of interviews is one of just many multiple things going on. Did you have a chance to speak with Alexandra at all about the project? Did you want to obtain a copy of the interview?

ACEM: Ideally, yes. It's the thing that I would share. I don't know what else you guys are doing. At some point, somebody will say, "Hey, you participated in this. This is where we're putting this information." I want everybody to be able to have access. We need to know that things like this are happening. That alone is really encouraging. Any sharing that I can do from here would be really helpful for everyone.

VAUGHN: Yes, and please reach out if you have connections or people that you can recommend to us.

ACEM: Okay, are you guys still doing the interviewing?

VAUGHN: It's ongoing. Yes.

ACEM: Okay, I have plenty of people who might be interested, but they thought there was a deadline.

VAUGHN: I can follow up with Alexandra and have her reach back out, or I'll find out and follow back up.

ACEM: Okay, that would be great. Thank you.

VAUGHN: Any final thoughts or anything else that comes to mind?

ACEM: Not at the moment. Thank you for the opportunity.

VAUGHN: Thank you so much, truly. You have given us an incredibly generous amount of time and energy today. I really can't thank you enough for the gift of that. Thank you so much, Jane, and we will follow up with you, okay?

ACEM: Okay, great, thank you! Have a good weekend.

VAUGHN: Thank you. You too. Take care.

[00:04:41] (End of May 31, 2020 interview)