Oral History with Sherrie Anon

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Interview with Sherrie Anon
SESSION 1 (4/29/2019)

TRAN: So let's just start with a basic introduction. When and where were you born?

[00:00:30]

SHERRIE: Okay. I was actually born in Cincinnati, Ohio, and currently displaced in Alabama.

TRAN: What do you mean by displaced in Alabama?

SHERRIE: I came down to—I moved down here with my husband about four years ago, he was in the military. He's retired military and had been gone for thirty years. So we kind of switched where we were living. Because I no longer have parents alive and our girls were in college. So there was nothing holding me to Ohio still. So—but I kind of feel displaced because if you've ever been somewhere like extreme North and gone extreme South or South and going extreme North, it's kind of very different. All around. Mentality, culturally, and a lot of other aspects. So you kind of feel displaced.

TRAN: That's a really—that's a interesting descriptor of it. And then, I know you mentioned your parents aren't alive now. But while growing up, can you tell me a little bit about your parents or your family background?

SHERRIE: Culturally, my dad was a—my dad was Sicilian Catholic. My mother was an Irish Baptist. And they were married about ten years before they divorced. So it was a norm—somewhat a normalized family up (until) that point. My mother did not work outside of the home that I remember. My dad did; he had a very steady job from the time he was seventeen until he retired. And my mother was basically a homemaker until after they divorced, and then she kind of did like factory jobs after that, until, you know, she retired. So, it was a pretty normal life until after that, and then it was kind of chaotic, because my mother had custody of—we the children, me and my brother. I do have one sibling. And she moved around very frequently.

TRAN: And what did your father do, from the time he was seventeen onwards?

SHERRIE: He worked at a manufacturing plant called Newtown, which was a supplier of electrical and appliance components to homes, like hood vents, and ceiling fans and stuff like that—whole house vacuum systems. So, if you see a lot of older intercom systems on the walls, of like the 1970s homes, you might see Newtown on it. And that was actually a local company in Cincinnati—based out of Cincinnati. It's no longer in existence. It's one that closed up and is, you know, everything overseas, in the nineties.

TRAN: So I guess like based on particularly—your father's occupation, what sort of products do you remember at the home that you grew up in, and did they affect you?

SHERRIE: I do not remember products, per se. I don't remember what we used for laundry. I do not even remember what she used particularly for dish soap. I don't really remember as a preteen

much about like household management things. I don't remember—except my mom cooking a lot. I don't believe my parents were very—I hate to admit this—cleanly. They were very cleanly about their bodies. I don't really believe—not that I remember our house being overly dirty or anything. And we didn't have pets. I just don't—never remember my mom being that meticulous, like, love-walking-around-cleaning-everything kind of woman. So that was nothing for me to really remember because it didn't really happen enough for me to—to instill it in my brain as "Oh, my mother was always cleaning," or whatever.

So I can't recall any product. Cleaning products—I don't even know if my mother used bleach in the laundry, to be honest. So unfortunately, I cannot remember those types of things and/or exposures. And of course every time we were constantly moving and living in like apartments or with other people, it was such an unimportant item to remember. Now that I think back over that. The only thing my mother did was she was a habitual chain smoker. She smoked while she was pregnant. And it's possible—it's possible that she drank alcohol too, because from my understanding of their marital affairs that was the problem. So, she was a drinker and a smoker. And I do believe that was while she was pregnant, because back then they thought smoking was okay. And even growing up I do remember she smoked in the car and we just would be gasping for air in the backseat.

[00:05:44]

TRAN: And then from this, did you show any signs of illness or sensitivity when you were young then? Growing up with your parents?

SHERRIE: No, I didn't, as far as I know, have any health issues. I didn't have asthma. I didn't—I don't believe had any of the childhood diseases like chicken pox, measles or anything like that. The only thing that happened to me is—I was accident prone. So like, I might (unclear) on my little Huffy bike and need stitches across to my ankle. I was mauled by a dog as a—like a thirteen-year-old and had to have my face stitched up. But I did have tubes put in my ears and that operation went okay. But when I had a broken nose as a thirteen-year-old—twelve- or thirteen-year-old—during the operation, they had to intubate me. They almost lost me because I have a genetic defect called a pseudocholinesterase deficiency.

And now that I know a little bit more about genes, it's the BCHE gene. And so, I had an issue with the pseudocholine drugs that they used to use back then for major operations. And that was the biggest issue and probably a hint towards me having a detoxification issue. Because the BCHE gene and pseudocholinesterase deficiency, it's not just pseudocholine drugs, it's the caine family. So things like that, my body has a problem—I don't have the enzymes in my liver to get those kind of drugs out of my system. So they can impair me to the point of—it has to do with lung function. That's an obvious issue of what it could do to me. But like the caine drugs—may take a little longer to wear off, like dental caine. I can use lidocaine patches, and they work really well for me. Where most other people are like, "Oh, I don't like these things. They don't do anything for me." So, that's because of that genetic defect. That's the only other thing major in my health that happened as a teenager. Other than that, no. No illnesses.

TRAN: I'm going to hand the phone off to Alexandra now. Thank you so much. I was just getting some basic questions.

[00:08:23]

APOLLONI: Hi, this is Alexandra again.

SHERRIE: Yes.

APOLLONI: So, just picking up from where Christine left off. So, do you think that your—this genetic condition that you've talked about—do you think that that has any bearing on your eventual chemical sensitivity? Do you know if there's any connections there?

SHERRIE: Well, I believe that it definitely set me up as a predisposition. So I've had my genetics done. And I also have the MTHFR genetic defect. But when you look into—when you run your oral data through a Genetic Genie, and you get the other homogenetic defects too, the double positive, you can kind of look through a lot of those and see the various ones that you may be like, "Oh, well, my liver is having a problem with this. And I don't do well with that." So I think it's a combination, because we know genetics is just like a ten percent predisposition and it's the lifestyle, you know, that's the gun, the lifestyle pulls the trigger. So, although I can sit here and go, "Yeah, I got some bad genes." I gotta go, "Well I got some bad genes and these are all the exposures I had to deal with over the course of my lifetime." Because the other thing was the pseudocholinesterase deficiency, is organophosphate pesticides. They make me very, ill like to the point where I could vomit, nausea and vomiting. So this is something that I should have been more aware of and cognitive of as an adult—a young adult, and throughout my life—but didn't because I didn't research it more before I was sick. Just always taking into account worrying about pseudocholine drugs, worry about if you're in an accident and do to the hospital, not to get those drugs. Not thinking, "I should stay clear of all this other stuff," you know, stay away from somebody coming around with a can of Raid or, you know, the glycosides, a lot of these herbicides or organophosphates based a lot of the pesticides used in agriculture and in our home, you know, and on our foods—never ever, ever registered with me that my body was going to have a hard time getting rid of these toxins. It was just that genetic defect alone. So I do believe it played a part but not entirely the culprit.

APOLLONI: Right. And so I want to shift now to thinking about when you did start to experience chemical sensitivities. And I know in your pre-interview questions you said that started to happen in 2011.

[00:11:19]

SHERRIE: Well, in 2011 is when I started having symptoms, from the formaldehyde exposure that started me down this rabbit hole: getting to the point of chemical sensitivities. But the actual chemical sensitivities hitting me like a brick upside my head, actually was at the latter point of when I moved into the new home in March of 2015—when we moved to Alabama.

APOLLONI: What was happening in—let's start at 2011. What do you think—what was the source of the formaldehyde exposures?

SHERRIE: So in 2011, I had changed jobs and went from working in a research lab to a corporate job. And that corporate job was in a high rise in a downtown building in Cincinnati. And so, after starting this job, after a few months, I started getting neurological symptoms. And at first, it was some of the sensory symptoms like facial numbness, which you know, they'll just say, "Oh, you got myofascial syndrome, or it's part of fibromyalgia or chronic fatigue, or you're stressed" or whatever. But the major one that was making us question things me and my health care professional, my doctor, was the muscle fasciculations. And if you know anything about muscle fasciculations, it's that tick: that eyeball twitch, that twitch in your shoulder. And what that is, is the brain is sending an electrical impulse incorrectly to that muscle. So that started happening. And the sensations started happening over the course of a few weeks. And at one point, it happened so bad for two weeks, straight in my thighs. Because it literally like moved from something in my head—my eye twitch—to my shoulder twist, to my thighs. And for two weeks, I was having this non-stop—like fireworks going off in my thighs.

And so, and then after that I noticed my muscles were atrophying in my thighs. So of course my primary care physician was like, "Okay, we need to get you to a neurologist" because our first thought was—if you've ever investigated neurological diseases—"It's ALS. Oh my god." Because that's a major symptom of ALS. Of course, it's part of MS and Parkinson's and a lot of other things. But it's a major symptom of ALS. Well, you know, after a few weeks, it started to subside. And then it would only happen after I exercise. So it would be like—part of this exercise fatigue because I used to ride a bike at least about three days a week. And we would ride about seven miles, me and my husband. And if we weren't riding bikes, we were walking (around) the neighborhood. But I noticed that I could go for a walk, a thirty=minute walk or a thirty-minute bike ride, and as soon as I stopped, these muscle fasciculations would just be going off in my legs again. And I would have to do something—I couldn't sit still because the only way to keep them from coming was to continue to be mobile and/or rub my legs. So this went on for several months. And you know, I went to the neurologist, they're like, "Oh, we don't think it's that." He just said "(unclear) benign. Benign articulation." I'm like, "Okay, benign, all right, whatever."

So I had to deal with this stuff for the next couple years. Well, what happened after the next couple years is—I was still having all these weird sensory issues, the muscle articulations, the fatigue, the exercise fatigue. I moved offices—into a office that had a bunch of file boxes in it, floor-to-ceiling. And within a week I was so like, just sick, nauseated. And I was getting this feeling every time I would go to drive home, I was feeling like I was going to pass out. And one day, I literally drove to the hospital ER and said, "Look, I'm going to pass out." And they did everything because I was like a forty-year-old woman and they go "Okay maybe you're having a heart attack," you know. You know, especially for heart attacks, strokes, and this, that, and the other. Like we couldn't find—they couldn't find anything wrong. And so I was having this like vertigo issue. And that started and then the nausea and feeling like I was going to pass out while driving. And this was going on for like another week or so. The three years later things are like, escalating, and it's all after I moved into this office. And—

APOLLONI: So this is 2015 now?

[00:16:29]

SHERRIE: This is in ‘14, the beginning of ‘14. I'm going through all these tests. I'm going to my doctor, like every week, like “Oh my god, I can't drive, my husband, you know, I'm having vertigo, I'm having nausea,” I'm going to the ER several times. Because I'm like, “I don't—I'm about to pass out while I'm driving home from work” and blah, blah, blah, blah, blah. And the funny thing is—and I have to bring this out because it's so relative—I moved my bromeliad plant into the office with me. And within a week it turned brown and died. I don't know if anybody's familiar with plants and how, obviously what you water them with and with the air they breathe also can really hinder them and kill them too. So I—you know, there was a lot of indications here. So, I ran—when I would take a few days off—because I was so sick and start to feel better as soon as I went back into this office. And I probably was dealing with this for only about three or four weeks in this office before I was like, “Oh, I cannot come back in there. I already know what it is.” I went ahead and ordered an air quality test online, ran the air quality test, sent it in. Because I was like I need something to tell these people. “Look, I know what's going on. Here's my confirmation.” And once I had that I was able to go to our corporate—which is, you know, it was a global company was based out of Chicago so that they could go to building management—and say, “Hey, you have an air quality issue on, in the suite on this floor, we need to do something about it.” You know which—they came and they investigated, we were the only company on that suite. They were like “There's nothing else on this floor.” I kind of already knew what was going on. Because I was like, “Well, you got fifty boxes here of old files. There’s formaldehyde in the paper. And there's formaldehyde in the ink.” I already knew this.

Just, I don't know why I had already knew it. It could have been because of our chemical engineers in the lab, or somebody had told me something one day, but I had already knew this. So I just didn't know how bad it could be. But you know, they said that they were up to code on OSHA, on air circulation in the building and they don't test for formaldehyde, they can only test for CO_2. You know. So my corporate basically made them take the boxes out and send them off campus. So they did that. And they made sure the building had the proper ventilation system and air switches going on throughout the building. It's just by then I had, I guess the chemical assault was so bad that even to go back after that I could—I couldn't even sit in the reception area. If I sat in the reception area for an hour I just started feeling like I was going to pass out. So my body was sensitized to the point where whatever residual was within that suite, it didn't matter. I was just every time I just went in there, I just started feeling sick. And then that's when I gave my notice, like I just can't work here anymore, you have some sick building issues going on.

And for me—because my body's had this chemical assault. I don't want it to get worse. I don't want to turn into an MS patient because I've had this exposure now. And of course, you know, two years is—for lawsuits and litigation purposes. I did contact attorneys. And nobody wanted to touch it for one: because I was past the two-year statute of limitation. But for (two), it was like, I was just one little tiny person sick, nobody else in the suite. You know, all the guys that were in there. Nobody had these extreme problems. They weren’t having these extreme problems. One guy talked about allergies all the time. Another guy talked about headaches all the time. Was it relative? Maybe. You know, did they care? No, they didn't care. Because, you know what I’m

saying? It was just me for some reason, this exposure, causing me these neurological issues, cascading me down this rabbit hole of chemical sensitivities. And, I just gave the job up. Well technically, they allowed me to work from home. But we were getting ready to go ahead and transfer down to Alabama. So to me, I was like, "I'm giving it up anyway." So that was three years of that.

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APOLLONI: And what was, what was—so you've spoken a little bit about the response from your employer. And it sounds like they, you know, kind of didn't do a lot for you in this circumstance. And so, did you did you spend a lot of time and energy trying to, you know, get them to accommodate you or change your workspace? Can you speak a bit about that?

SHERRIE: Actually, the, what the funny thing is, is they actually really did accommodate me. Because they knew that I was able to—they knew for one like "Hey, she got an air quality test," even though corporate, the building management tried to say they sent it to some specialists in Virginia. And they said that, "Oh, that's no big deal—that that amount of formaldehyde is no big deal and won't hurt anybody. And oh, you know, the EPA and OSHA and everybody else says "Okay." And I'm like, "Okay, well, it's okay for other people, but for me it caused an issue." So, they actually didn't want me to leave to the point where they allowed me to work from home. They wanted me to stay there, they were like "We won't tell anybody, but you can work from home." So, until I actually left—sold my house and left—I worked from home. And had I have stayed I would have still had that job. So, they were willing to accommodate me. And it wasn't even a chemical sensitivity issue. Well, I guess it was, because I was sensitive to be in that suite now. I was sensitized to it. And I didn't realize, to what extent at this point I was getting, you know, worse, and worse, and worse. But, yes, I would like to say that at this point, they accommodated me. But it wasn't a chemical sensitivity, like a fragrance issue at that point. It was a formaldehyde-causing-neurological-issue point. And so technically, allowing me to work from home was an accommodation, a very adequate accommodation.

APOLLONI: Got it. And so that was all happening between 2011 in 2014.

SHERRIE: Correct.

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APOLLONI: And so, what happened next for you?

SHERRIE: For the next move, which brought us down to Alabama, that happened in March of 2015. And that's when we moved down here and we moved into a VA foreclosure home that we had bought, that had been sitting closed up for two years. And, so, by the time I got into it, it was a four-year-old home that had been tightly closed up for two years. And it still had a very strong new home smell to it. So, although I realized that right away—I figured I could mitigate it. So, we did a lot of everyday: we would open up the windows; turn on the fans; have air being blown out of one window and sucked in another window; I had a UV/VOC filter put on the furnace. You know, we tried to mitigate it as well as we could. But within in a month, I started feeling the severe (unclear) again. And by the second month, it got to the point where my body couldn't

handle the exposures that I was dry heaving for three days. Literally. I literally was like (heaving noises), and I just did this for three days. And I literally was left out on the back porch on a cot—like a big—I can't remember what you call those things. But I just I slept out on the back porch for three days. And the dry heaving just was non-stop. And I was like, "I can't even do it. I can't be in the house. I don't want to shower in it." I was like, "I gotta go." And I went and moved in with my daughter who was renting a home by then—or no, no, no, she was living in an apartment complex by then.

But the damage was done. And once again, I did an air quality test and it came out more than what my office that had made me sick came out. So I went from an elevated exposure to a high exposure. So it wasn't just elevated, it was high levels of formaldehyde. And I noticed that something was happening chemical sensitivity wise because all of a sudden, I had this extreme heightened sense of smell. Like it was a 3000 square foot home and I could smell that my husband put deodorant on across the house. And all of a sudden I was like, "Oh my god, I don't—like I feel a little nauseated, what's going on." And it got to the point when I started getting nauseated from the deodorant to the body wash and the hair stuff. And when I went to stay with my daughter, it was just full blown. Like I couldn't—if somebody came around me, I just wanted to—I would just getting nauseated and start (heaving noises). You know, and that's when we realized, okay, and that's when I started digging and searching and looking for answers. And at that point, I realized, okay, this has really affected me now and thrown me down this rabbit hole of chemical sensitivity. And we could just detoxed from there, you know: deodorants and body washes and laundry detergents and everything. So that's what I realized it was the—I was at the point of no return.

APOLLONI: And how—how did your family react to this? Like, was your—was your husband supportive in trying to help you detox or?

[00:26:49]

SHERRIE: Well, he doesn't have—he's not a like—a medical background or research background, you know, a health and wellness background. He wasn't—he's not the typical—I was, for the most part, my entire life kind of health conscious. I was the—I like to work out, I ate things like salads, I didn't drink, you know, I didn't drink pop, you know, I would drink them when I went out. But it wasn't something like—my kids can tell you— we didn't have pop in the house. We didn't even have things like Kool Aid. It was 100% juice. And, you know, we (drank) water.

I wasn't a total health nut freak. But there was an air of trying to always be healthy my entire life. And so, we already used fragrance free laundry detergent. And although I use dryer sheets, they were the fragrance-free ones. And I would cut them in half because I was like, "Well, you know, I really don't want all these chemicals on my clothes." I knew that they weren't the greatest, but like, I felt like I needed them because I didn't know anything else. So he, I'll be it with—I don't want to say clueless. He didn't know what to do for me. Although, he believed in me and everything I explained to him and told them. So I didn't have a husband that had cognitive dissonance because he didn't care. He had it because he didn't really know or understand. But as I would—you know—they knew I had a research background. So they knew that as—when I

explained things, I just wasn't pulling things out of my—oh okay—out of thin air. They knew that I was actually researching things. And for the lack of a better phrase, I would dumb it down. Like, “Okay, this is what's happening with me, it's a neurological issue.” And so, even though he may not understand the technical points of the medical or the science, my husband basically was okay with whatever I did. If I changed his deodorant, as long as it was a fragrance or gel, he didn't care.

As you know, he didn’t deal with—I did all the shopping. So whether it was the body wash, or the soap, or the shampoo, or—as long as I found him what he wanted, and it was fragrance free for me, he didn't care. So he was more than willing to accommodate me. Because I mean, you know, when you watch your spouse, either passing out in the house—because that happened a few times, like I ended up out of bed and just hit the floor when you watch her go through all these neurological problems for three years, and all you can think about is “What the heck's going on with my spouse” He the type of guy like, if I pass out in the—walking in the street, or in the house, he's is going to pick me up and take me to—you know, like, “I’m here to save my wife! I'm going to rush into the hospital!” You know what I mean, so I never, like—I knew, even though he may not have understand, he was concerned enough that he was like, “Okay, whatever it takes, whatever we got to do. If we gotta live in the woods, let's do it.” So I had that support.

And then of course, my daughters were the same way because they literally watched this transformation of this healthy—what they thought was Wonder Woman mother. You know, the mother who literally could change the tires on the car, and fix everything around the house. They watched this woman just go from that to being so sick and inebriated, and spending days, and days, and days in bed for like an exposure—would make me in two or three days in bed. You know, and so, especially if I got to the point where I was nauseated and vomiting, I literally could go home, like, “Oh, I'm going to take a nap.” And the next day, it'd be like, “Oh, wow, it's been twenty-four to forty-eight hours, you know, what's going on?” So as they saw all this transpire, you know, they were equally concerned for me. But my girls were equally okay with making sure that the—whatever we had to do in our lifestyles, accommodated me. So I've been actually one of the rare ones who have been blessed by having a very supportive family.

Now, of course, granted, they've always put their faith in me and my knowledge. And even if I had a lack of knowledge, I've always taught them if you don't know something, then you go find out. Ask questions: figure it out, find it out, ask somebody that does know. So be inquisitive. And they said, “They knew that I wasn't going to be telling them something that didn't either make sense,” or that “I was just doing it because I wanted them to.” So I have a little bit more faith in that my family has been a lot more understanding and accommodating than most.

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APOLLONI: And what was the reaction of the medical professionals you were working with? Did you—

SHERRIE: Well, when I was when I was in Ohio, and I was having all these neurological issues, my primary care was very, very although she didn't know what was going on, either, she was very understanding. And when it got to the point that we figured it out—figured out it was

an air quality issue, at three years later, at that point, I had been through two neurologists, one ear, nose, and throat, one allergist. And the second neurologist said that they don't do anything for chemical poisoning, like formaldehyde. He was like, “We don't treat the disease until it's at the disease point. when you got all these symptoms that say, ‘Hey, you have this, this, and this,’ then we start treating you.” So just treating you for exposure that are causing all the same symptoms, he's like, “We don't, we're not—you need to see an environmental specialist.”

And so at that point, I thought, “Okay, I need to see an environmental specialist.” And I figured I'd do that once I was down here. Well then once I got really sick, it was a little bit different down here because I—first I was going to a base military doctor. But I wasn't really going to her for these issues, because I kind of already knew what was going on. It was like, “Okay, I need to avoid this.” I was also trying to seek out an environmental medicine doctor physician. So, in the midst of that I changed doctors from the base doctor—military doctor—to a well, I tried to find a primary care civilian doctor. The first one, I tried in a city—a larger city—about thirty minutes away—would not even come into the office and told her nurse—kept telling the nurse to come in and ask me “What does she want me to do for her? What's wrong with her?” And so basically, initially, she refused to come into the office and see me because I told the nurse, “I am having these issues with chemicals. I'm having this chemical sensitivity issue, I need some help trying to figure things out.” And the back and forth with the doctor not wanting to come in because she was like, “I have no idea what to do with this person.”

And to be honest, I don't know what that doctor was actually thinking. I don't know if she was thinking I was a mental case, or literally was she's like, “I am so clueless. I just don't want this person as a patient. I don't want a complex patient.” Because I understand some of them are like that. They just don't want a complex patient. They just want the normal patient that has high blood, diabetes, thyroid disease, and then he’d write me a pharmaceutical and be done with it. So, when I told I told the nurse, I basically said, “Look, I used to work in research, I just want to have a conversation with her.” And when she got her to come in the door, I said, “Look, this is what's going on with me. I just need a doctor.” I said, “I'm trying to find a, you know—I need a regular doctor, and then I'm going to be seeking out an environmental medicine doctor.” And she basically told me, “I should go see another allergist.” And I was like, “That's fine. I'll go see another allergist, but I just need a primary care doctor too.” And I just, I left there feeling like, I knew she didn't want to be my primary care. And so, I booked for another primary care doctor, in addition to seeing the allergist who was from Pennsylvania, so he gave me a little bit of—he put my mind at ease. But he said he “knew of chemical sensitivity. He knows enough about it to know that there's not much you can do for it. It’s just a lifestyle of avoidance.” And he gave me nose spray. He said maybe this will block your olfactory systems. And I was like, “I'll try it. But I don't think that's the issue. It's a neurological thing.” I mean, he, you know, he was honest. He was honest.

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And so I did finally found a primary care doctor who granted was 100% upfront with me. He said, “Look, I don't understand what's wrong with you. I don't know what to do for you. The best I can do is give you a prescription or a vaccination.” And then he looked at me and said, “Which I probably doubt you would ever want.” And I was like, “Thank you for that.” And fix a broken

bone. He said, “But other than that,” he was like, “I don't know, I can't do anything. I don't know what to do for you.” And I told him, I said, “I'm going to speak out an environmental medicine doctor for this.” And he said, I've never ever heard of that. He literally got on the laptop and googled “environmental medicine.” He said, “I didn't even know this existed.”

[00:37:05]

I was like, “Well it does.” And he was like, “Well there's one in Pensacola, it's two hours away.” I said, “I already know I'm trying to get an appointment to see this woman.” I said, “I just need you for when I need you, for the purposes that I say I need you for. So if I want a prescription, you're going to write a prescription, or if I asked you to run a test, or whatever, I just need you to do it for me.” And he said that he was fine with that. I said, “Well, great, you have an understanding, and I have an understanding.” And he's like 500 pounds. And I have an issue with health care professionals who don't take care of themselves. But I was like, “You know what, this guy was fine with me. And so I'm going to be fine with him.” And so we have this love-hate relationship. And it is what it is. But when I need something, when I need a pharmaceutical, you know, when I need a prescription refill, I go to him. When I need a test done, I'll tell him to test. And a lot of times he just looks at me like why do you want this path? And you know whether it's my B's or my folate or my histamine levels, you know, he just orders them. And then that's it. Or, you know, if I deal with something other. You know, like right now I have spinal issues, you know, he does my referrals. And that's it, I use him for what I need him for. And then at the end of the day, I know he cannot do anything for me with the chemical sensitivities. Well he did at least document in my medical records that I have—you can have it under allergies, formaldehyde.

So I know he doesn't understand it, but at least he was smart enough to put it into record. And he knows that I can't deal with the fragrances and stuff. So when I've never had an issue while I was in the office with him or the nurses. But there was an issue because they started to use nurse practitioners. And the first time I had to see her, “I was like I have to wear my mask.” And I sat across the room from we're from her and I tried to tell her and explain to her my issues. And of course, she was a little oblivious to it. But I was like what you need, I gave her some pamphlets. And I was like, “You need to read this to understand a little more, but I can't be in the room with you if you're going to smell like a Bed Bath and Beyond store.” And she's like, “Oh, yeah, I understand. Well, you know, I don't put that much on above blah, blah, blah.” And I kept thinking, “Okay, this lady is inundated from head to toe.” She's got, you know, the—I could see all the heavy makeup, this, that, and the other. And so, the next time I went to make an appointment, I told them that I did not want to see the nurse practitioner. Because one it was unnecessary. And two she is inundated with chemicals that make me sick, so this is an issue. So the next time I went in—although I had requested it be a doctor-only visit and that I refuse to see the nurse practitioner because of the this particular issue—she felt the need to still make—come into the room. I put my mask on once again, and was like, “You know, I have issues so I'm going to stand back from you.” And you know, I answered her questions, I was polite to her. But once again, when I called to make my next appointment, I said “Look, this is a problem. I refuse to see her which means I do not want her to come into the room.” I said, “I have complained about this the last time when I made my appointment. And so therefore if she comes into the room, I am

going to make scene." So the next the next time and every time after that I've never had to see her since.

APOLLONI: It must be so frustrating to have people just disregard you like that.

[00:40:50]

SHERRIE: Correct. And it would be different if I was just you know, the common Joe Blow farmer from around the corner that they deal with, and they thought I was a basket case. But when I stand my ground, when I tell you, "Look, I used to work in research. I'm not the dummy that you're dealing with, or the psych patient that you think I am. I've got things that I've told you, that I've explained to you. Now, whether you understand or not, I still demand that you respect my request." So that's the biggest difference between me and most people. I'm the stand-your-ground-type of patient.

So, it's been a little bit easier for me to deal with this particular doctor's office because I've been able to have the understanding what the doctor and stand my ground. And I have no problems with wearing my Vogmask. And so it's—it's apparent. And if I have problems in the waiting areas, I will tell the people at the front desk, "Look what's this?" I'm like, "It smells like somebody spilled a bottle of Cologne." And they'll be like, "Yeah, the old—man that came in before you smelled like he put the whole—" whatever, you know. And it's just a situation of they've got to air it out. And you know, I did notice—you know—and I tell—and I asked them, when I see them putting hand sanitizer on, "Okay, please don't use that." If I see that they're going to put hand sanitizer on, I'd be like, "I'm the one with chemical sensitivities. Please don't use that." And they'll say, "Oh, yeah, that's right." You know, so I get a little bit more respect. So, that's my medical care down here. Beyond (that), I have seen the environmental medicine doctor also.

APOLLONI: And has that been helpful? Has that been like a different experience?

SHERRIE: Let's see. So this is the extent of the fruitfulness of seeing this environmental doctor: this environmental doctor suffered from Lyme disease herself; so, she has been battling this, And her ability to be in practice is questionable. But she did understand me. She did understand how it was affecting me, because I believe to an extent she was sensitive too. And/or becoming sensitive because Lyme disease. And she did have a very small office with only a one nurse and one front office person who was not aware of, you know, like what needs to be done to accommodate me. But they, you know, once I told them once or twice, they understood. The nurse kind of understood, but I don't believe she understood it enough to where—because I'm not sure there was a lot of patients like me going there. So, I may have been the only one. But, I never really noticed anything enough to where I had to complain about it with the nurse. So, they knew like I couldn't be there if they had just cleaned or if like there was scented soap in the bathroom—of which I did say something about the first time I went there—and they immediately switched it out. Because they didn't—you know—they're not realizing it because if they're not—if these environmental doctors aren't getting chemically sensitive to patients, then the staff isn't realizing all the things that go along with treating somebody like us, or accommodating us.

[00:44:36]

So once I brought something to their attention, it was like, “Oh, yeah, you're right. She's supposed to be a (unclear) And oh, yeah, you're right. Oh, yeah, that hand sanitizer at front desk is Apple scented and bad.” You need to tell people, you know, like, when they come here these little old ladies can't be coated in Elizabeth Taylor, because I can't sit out here with them. Or I’m going to scare them when I put my mask on because they're going to look at me, you know. So this particular doctor had no suggestions other than avoidance and trying to detox my body, and use supplements. And she had me for one year do what's called LDA (Low Dose Allergen) shots, which are low-dose immunotherapy shots. And so those are typically used towards people that have like food allergens, and other environmental allergens like pollen, and dust. But they do have a chemical concoction component to it. So, I did the chemical concoction component for a year. And so, when I told her, “Look I don't think these are really doing anything to make this situation better. Albeit, I do believe it's hindering me also.” She suggested I do the entire allergen chemical cocktail.

APOLLONI: Yes.

[00:46:08]

SHERRIE: And one—and this shot is a—it's like an inner dermal. It goes right—it’s not below dermal its going—like she goes under like several layers of skin. It’s like when you get the allergy testing done: they don't go—they go right into the skin and deposits the allergen. It's like that. So they inject it right up under your—between your skin layers. And when they did that the last time, my arm swelled up like a football. And I tried to tell her I didn't want to do them anymore. But you know, she insisted and I thought like, “I'll try one.” And after that I decided I think I'm going to stop seeing this Environmental Medicine doctor. Because I was like at that point, you know, there's not much you can do for me. You know I have to live a lifestyle of avoidance. But you want me to keep trying these $200 shots every time I come into your office that I told you that we are now a year into, and they are not working. If anything, I’ve become stagnant or worse. And it's getting me nowhere.

Now albeit she had other therapies I could have tried like glutathione IV and sauna. It was a two-hour drive for me to get in there. And my husband was driving me back and forth for you know—for long trips I don't like to drive is in case I get sick or an exposure that makes me sick. And there's—that's a problem. So, I dealt with an environmental medicine doctor for a year. And then approximately a year and a half ago, I tried an integrative doctor medical doctor in Florida, who said that I literally confirmed with her nurse that she understands and treat chemical sensitivities. The nurse confirmed, “Yes, she does. She's willing to take me on as a patient. She was a pediatrician. But she also did integrated health for women.” So she had a dual practice on one side was a pediatric. And on the other side was an office for integrative medicine for women. Now I read her bio, her CV, she trained under Dr. Weil. If you know—if you've read any of his books, Dr. Weil is big on nutrition. And he does talk about like environmental stuff. Impact. Even if you look on his website, he's had articles about fragrances.

[00:48:14]

APOLLONI: Oh, okay.

SHERRIE: So, I figured looking at all this, that, “Okay, this integrative doctor—that is, medical doctor—may have something else that she can do for me.” I made sure I was like, “Look, I cannot be in an office,” and it's a pediatrician’s office too. I'm thinking “Okay, I should be safe. I cannot be in there if you guys use hard cleaning products, or there’s things like plugins and air fresheners.” And the girl was like, “Oh, no, we don't use that stuff.” Like, okay. The irony of the situation. Upon entering the building, I was like, “Okay, I'm behind this old woman. I'm smelling fragrance, like crazy. It must be old lady fragrance?” So, I gave them the benefit of the doubt. I was like, okay, this lady here is inundated with it. But, you know, let me get into the building and see what I'm dealing with. I did use their bathroom. And I was like, the soap was scented. I was like, so I was like, “Okay, here's a problem.” And then I felt some can of air freshener for if I guess someone did a poo. I'm like, “Okay, this is unnecessary.” And, really? And so I thought, okay.

When the nurse came and got me and took me over to the integrative side into the office—where she does integrative medicine for women—I filled out the paperwork, and then she took me into an exam room. And I immediately—immediately could tell that there was scent in the air. And I said, “Look,” I said, “Are you using air fresheners or something?” And she was like, “No, we don't use that stuff.” And I looked around, and I said, “Look,” I said, “There's a plugin right there.” I said, “What is that?” And she said, “Oh, I didn't realize we had that.” And I said, “Well, what's this over here?” I said, “Is this an essential oil on this stuff?” And she said, “Oh, yeah, we don't have that on right now.” I said, “No, you don't,” I said, “But if you're using these products, these VOCs are in the dry wall. They’re in the furniture. They’re in—they’re on the surfaces.” I said, “This is exactly what I called and asked about. This is a problem. I have chemical sensitivities. Do you want me to throw up on you?” And she was like, “Well, hold on, let me get you out of here.”

She took me out of there. There was a door to the outside. To this—actually, you know—meeting room. She opened the door and turned on the fan. She's like, “Let me really air out the room for you. Maybe this will help.” I said, “It might help.” I said, “But this is a problem.” I said, “I'm very concerned.” I said, “I asked, I literally asked you guys before I drove down here for two hours, if the environment was safe for me, if she understood chemical sensitivities enough to treat it.” I said, “This makes me not have any faith in her.” And so, they aired it out for about thirty minutes or so. They kept the door open. And I finally was like, “Let me go into the room and see if I can tolerate it,” which I did. And I had to put my—I only had a vogmask—but I had put it on. And I went in there and I waited for her. And she came to the doorway. And she looked at me.

And at that point, I was angry. I was hot. And she said—she's like, “I'm sorry, I didn't know.” Blah blah blah blah. I said, “Look.” I said, “Beyond the fact, that I have chemical sensitivities, you’re a doctor, and this is a pediatrics office too. That plugin is putting all kinds of pollutants into the air. Endocrine disruption.” I said, “You know, those aren't even good for asthmatic—and I'm sure you're treating asthmatic children in your practice.” I said, “To the fact that you use these products, and you're acting clueless right now to me,” I said, “makes me have a little faith in your ability.” And she was so caught off guard by me—being so you know—like standing my

ground, that she literally—I don't know if she was shaking—but she was like, “We can—we can—we can —we can postpone this appointment. We can do this another day. We can even do this—we can do this over the phone if you'd like.” She was like, you know what I mean, “We can reschedule this appointment.” Blah blah blah.

And I said, “You know what, I drove two hours to see you.” I said, “I am here.” I said, “I am dealing with this.” I said, “You need to sit down and you need to have this discussion with me.” I said, “Because I'm not going to waste the fact that I drove two hours to, in addition to the fact that I had a conversation about all this before I came.” I said, “So you know what?” I said, “Let's just go ahead with the appointment.” And so, we had the appointment. And she just—all she could do for me is she ordered a urine tox (toxicology screen test) and a fecal tox on me. Which, the best thing I got of dealing with this integrative doctor is that she did these two tests on me and a glyphosate test. So, I was able to understand what my body was doing on a level—as far as what toxins were basically, in my—showing up in my urine and my fecal. So, she was able to confirm that I had a Candida issue at that point. Which I do, I have a very bad Candida issue. But I don't—I don't believe I had a parasitic issue. And I didn't have a glyphosate level issue. And that may be because I eat—we eat very—we try to eat very clean and all organic.

[00:54:20]

APOLLONI: Right.

SHERRIE: So, I’ve not been back to that doctor either

APOLLONI: Yes, I can't imagine why. I would love to chat a bit now about some of what you were saying before about your research background and how that has shaped the way you've approached illness. Can you talk a little bit about what your research background is, and—

[00:54:16]

SHERRIE: I worked for an orthopedic biomechanics laboratory as their administrator, and also a clinical research coordinator for the division of orthopedics. So, I dealt with the—basically the regulatory matters that had to do with the research lab. Because we were an animal research lab. We had to deal with IRB.

APOLLONI: Yes.

SHERRIE: So, we had—or not IRB—we had to deal with IACUC (Institutional Animal Care and Use Committees). And we had to also deal with a lot of chemicals in the lab for the researchers. And I dealt with engineers, and they were developing a scoliosis staple. And so I dealt with basically the administrations for the lab, including the regulatory requirements. And I dealt with the clinical research coordinating for the division, which was surgeons—orthopedic surgeons—residents and fellows. Because they don't deal with pharmaceuticals, their clinical research was more records, and data. So, the only like ongoing clinical research they had would be more of like algorithm studies: post-surgical algorithm studies of collecting data—surgical

data. And there were several national study groups that they were in, so a lot of their clinical research was records they might write up, write up a case report and submit it to a journal.

They might pull—we had a couple, even our even our nurses were, you know, a lot of them would try to do research also. And we've tried to promote that to—all our residents and fellows that came through were pushed to do something in research. If it was just a case report. But a lot of them would pull data on patients, whether it was a lung function before and after. Stuff like that. It might have to do with the coagulation drugs that they use—blood banking versus coagulation—so there was just a lot of clinical research that had to do with surgical patients. So there was the regulatory component of that, which is (unclear) with human centric research. Of course, you know, this IRB. So, I had to deal with the IRB, and I had to deal with the IACUC, I had to deal with the clinical research of the surgeons, residents, fellows and nurses. And I had to deal with the biomechanics lab. So, what in addition to all that I was tasked with filing all of the abstract, posters, and journal submissions for all of these people, to all of these different orthopedic society, on a yearly basis.

APOLLONI: What university where you at, again?

SHERRIE: This this was a Research Hospital in Cincinnati that partnered with a university

APOLLONI: Okay.

SHERRIE: So, it was a brief—it was—so basically, it was a research or a hospital that did partner with a university.

APOLLONI: And do you think like having this experience working with researchers, it sounds like that—

SHERRIE: Yes.

[00:57:57]

APOLLONI: —made you—has made you look up almost like a more effective self-advocate when you've been dealing with doctors. Do you think that's true?

SHERRIE: Yes. Yes, because I know how to one: find the research, and (two) look at the research and know like, well, how valid is this research? Was it a small pool? Was it a large pool? Was it just—you know—because a lot of people like, “Oh, look at this study.” I'm like, “That study? What study? No, that's not a study. They just looked at a bunch of other studies.” I'm like, “That's not a real study! People, no, that's—okay.” So you know—so I was able to look at things a little bit more easier. Although I don't sometimes know the technical or the medical part as much as I would like to, I can at least look at something and go, “Okay, this is what they're saying is going on, you know, and if I don't understand it, I can take pieces of it and look into it more.”

So, I've been able to take that, and you know—because when you first get chemical sensitivities, and you start googling stuff, you're liable to get depressed. Because you know, things like Wikipedia—although it's getting better, you know—it's got all this psychological stuff. And you're looking at yourself going—and to the average person, they're questioning their self like, "Oh my god, am I crazy? Is this—am I psychotic? Am I bipolar? Am whatever—is this all in my mind?" I was able to discern, like, "No, this is not all in my mind. It's a neurological thing, because I understand chemicals. And I understand that VOCs affect your brain." And I was able to actually read like studies about formaldehyde, and it causing this accelerated brain apoptosis, and go, "Okay, well if this causes this, well then it's gotta be doing damage."

And it made sense, because I had an MRI that showed two brain lesions after I had moved into that office and was having the really bad symptoms, and I had this brain crushing sensation for a week. Literally, it felt like somebody was squeezing like—you know—Hannibal Lecter had opened up my brain and was squeezing on it—having his way with it. My doctor was like, "Let's give it get you in for an MRI." And that MRI showed two brain lesions. And I thought, well, I've had MRIs before, because I've had migraine. I was a migraine sufferer and I've never had brain lesions there. So, I could sit here and go, "Okay, like, I've got a little bit of brain damage going on." You know, "What could it have caused—could it be a correlation—while it's possible." You know, you have to sit there and go, "Because we know the studies say that this causes this." So I was able to discern a lot of things a lot more quicker.

So did it help? Absolutely. I'm going to say yes, it did. Not just in making me dig for information—and not just look at websites—but actually dig in the research. But it also gave me an air of—what am I going to—how do I want to say this? For lack of a better phrase, it gave me the balls to stand up to the allopathic doctors. Does that make sense? In other words, it gave me confidence to know when I wasn't going to take some doctors dismissive behavior.

APOLLONI: Yes.

[01:01:56]

SHERRIE: So—and like I tell my daughters, like—if somebody's treating you dismissively, like you don't know what you're talking about, like they're telling you, "Oh, don't—," you know, they're being dismissive about something, I tell them to blow wind up people's asses. Other people who are being dismissive towards you don't know who you are, or your background. So, a lot of people are dismissive towards you, especially when they're from either a legal or a medical background, because they feel like you don't have their knowledge, or you don't have their background. Therefore, they can be—they can talk to you in a degenerative way. They can be dismissive towards you; they can blow wind up your ass and tell you something that's not true and hope that you'll just accept it and go away. So, I feel by having this confidence because of where I work—

APOLLONI: Yes.

SHERRIE: I can blow that win right back up their ass. And when I say, and believe me, when I tell them, I used to work in research—and they don't know what capacity—they literally look at

me like a deer caught in the headlights. Like, “Oh, shit, I need to be careful of what I say to her.” So , it's very helpful. And it's also been helpful in going to other people's doctors’ appointments with them, like my mother-in-law. Because I don't—when the doctor says something, it bothers me that people don't question them.

APOLLONI: Right. Exactly.

SHERRIE: They don't ask more questions; they just accept the pharmaceutical and they don't ask questions, and they don't probe for further information or for—you know—for them to go over test results and this, that, and the other. So, to me, I'm going to be that questioner. And to me, I'm going to tell them, “I'm asking questions. And there's a reason.” And when I say I used to work in research that makes them take me one—more seriously, and two—answer my question more effectively. This has literally happened with my mother-in-law. And it is also happened with my husband going to VA appointments. So, my thing is, is you can coerce my mother-in-law into something, and you can throw a cart full of pharmaceuticals at her. You can coerce my husband into a vaccine, and you can throw pharmaceuticals on him. But when I'm in the room, and I question you, or I state something to a fact. Like I state, “You know what, if you told my husband, he's not going to get VA benefits, because he doesn't take a vaccine, that's coercion, and I can have your license pulled,” then they don't say anything more about it.

So there's a difference when you start and I preempt that with “I used to work in research.” The attitude totally changes in that scenario. Because at that point, one—they don't know that I was just administration. Two, the seven assumptions in seven seconds rule applies. They start making assumptions. “Oh, shit, she used to work in research. What did she do? Is she a scientist? Is she a—,” you know what I mean? They don't know. They literally don't know. And so, they go from having an air of dismissiveness to me and or whoever I’m accompanying, to an air of, “Okay, let me watch what I say, let me watch what I do. Let me be better at explaining myself.” You know, what I'm saying? The entire outlook and how they treat you changes. Unfortunately. And so I do—and I'm not going to lie, I use it to my advantage. It breaks my heart to see other people in these forums online, and the struggles that they have. Because that's—it's heartening. It’s heartening. Because a lot of people don't have the support that I have. And they don't have the *cojones*, and I just want to be—I wish I could be in the room with them.

[01:06:11]

APOLLONI: Could you talk a bit more about your involvement with the kind of larger MCS (Multiple Chemical Sensitivity) community, whether that's online or through different kinds of like activist projects?

SHERRIE: So, so right now, I have—of course, everybody's on social media, with, you know, all these groups, which is great. Because before that you only had websites and forums. You know, websites that provided you a forum capacity. And that was great. And now we have social media. And that's great. Now we can connect with people globally. And so of course—and dealing with this, learning about this, and wanting to connect with others on this, we've all relied on social media. So, there's got to be ten or more groups out there for chemical illnesses, or environmental illnesses. And all this, and that, and the other. So, I've been—I’m in all the

groups. I try to participate as much as possible, but I don't really like to get involved with the, "Oh, what kind of shampoo do I use?" Or, "Oh, my God, I'm reacting to this, what do I do?" I'm outside of that. I might partake in some of those conversations with a few suggestions. But what I like to partake in is when we all get together, and we try to educate others on other pages, you know. Whether it's a hospital, and they posted something about I don't know—they may have posted something about breast health month or something another. And then I might go in and start talking about posting about the links of environmental causes of breast cancer, and how there's research out there, you know.

So a lot of my posting, is I'm posting—I'm trying to bring up the research and how it relates to—whether it's a post about breast cancer, or somebody, somebody talking about diabetes, or, you know. Because there's just—there's a lot of research, and it's not out in mainstream media, about all the environmental links to these illnesses that we have. And it's from our everyday illnesses to our auto immune diseases to our neurological diseases, including like Gulf War syndrome. Which I get—I'm on a couple email blasts about from some Gulf War vets—because when I when I was in the military, I was in during Desert Storm. And my husband is a desert storm veteran. We have several friends that I still communicate with that were stationed with us that went over also. So, I try to keep up on that because there is an overlap, you know, of Gulf War illness, and fibromyalgia and chronic fatigue. So there is that overlap of these illnesses and the co-morbid symptoms that they have. And with Alison Johnson's books that I've read—you know—knowing Gulf War vets, a high percentage of them have varying degrees of chemical sensitivities.

[01:09:40]

APOLLONI: And so you were overseas during the Gulf War as well. Is that right?

SHERRIE: No. I was not overseas. I was in the military. Me and my husband were stationed together in the military. I was actually pregnant with our first daughter. So I was not—I was not shipped off, but he was. Granted, it saved me exposures to: bromide pills, anthrax vaccines, burn pits, all the organophosphate pesticides that they use in the tent, around the tent, on the uniform. If I had to go through that—I hate to say—I probably would have been one of the Gulf War vets that was so sick when they came back that I had chemical sensitivities in my twenties. So, now knowing that mine was probably a toxic body burden level accumulation over my lifetime. Something like that may have hurt me extremely early and caused this earlier than what had had. So I do try to stay up on the research that's going on with Gulf War vets, also. And I also try to share things in those groups also when I see certain postings. You know what I mean? I bring up the fact that they need to say, "Our Gulf War veterans need to: stay away from environmental toxins, what they use in their homes, check their air quality, be cognitive of the products you're using." So I make sure that I'm still taking all this information, and I'm cross-posting it. So I stay—I try to stay active in all these groups. But what I've also been doing is trying to—for the last year or so—contact Mary Lamielle and work with her. I wanted to volunteer work for her because I knew of her from other people mentioning her, looked up her website, and knew that she was collaborating with the ADA (Americans with Disabilities Act) Access Board. Of course, I did not know to what extent. But now that I have talked to her one time briefly—after trying to get a hold of her for a year—and I made a public comment in the April ADA Access Board

meeting over the phone. I've been able to ascertain from what—I've talked to the ADA Access Board person and her. She's been fighting—I don't want to say fighting—but actually she's been working with the ADA Access Board for thirty years, trying to get them to do work for people with chemical sensitivities.

And if my understanding is correct, the reason that the Access Board does not go outside of the realm of just making their meetings fragrance-free, is because the Access Board deals with the built environment only. So all the rules and regulations around access, and disability access, has to do with the buildings themselves, you know. And the physical aspect of this building. So in my in my public comment—which was wonderful because I really didn't go over my public comment with Mary Lamielle. Although I knew she was going to be a public commenter and has been a public commenter at every Access Board meeting for the last thirty years, which obviously means she's beating a dead horse. I went over my public statement with a woman who's in all the groups called Dori Blacker. And if you get to interview this woman, she's absolutely wonderful. She is very prolific. But she's like me. She's a talker. She is a say-what's-on-your-mind kind of woman. She ain't gonna sugarcoat it. She is very to the point. She doesn't—she's not gonna honey coat it. But she's very good at like ideas and things. And her knowledge base is wonderful. She's in her sixties. But she understands nonprofits; I think she's worked for them. I think she understands politics a lot more. So, she is wonderful. But she gave me—she brought up this wonderful thing that made me question the same question to the Access Board, which is all the—albeit they're dealing with this built environment—indoor air is a part of the built environment once it's built.

[01:14:31]

APOLLONI: Yes.

SHERRIE: And although it's ambient—you cannot see it—it is in essence the gut of the building. And it is part of the built environment, and should be considered an accessibility issue by the Access Board. So I am hoping that if anything my public statement—because I'm only one other person than Mary Lamielle that's spoken I guess in thirty years. I'm hoping—I'm hoping that they like—like that brought up some red flags. And so the wonderful thing that I've been doing is trying to take the information about these meetings and throw it out there on social media. Because when I realized that Mary Lamielle has been beating this dead horse for thirty years and not getting nowhere. The reason that I figured this out is because she's a one woman show. Her foundation is a one woman show. Everything she does is one woman show. She's trying to be this advocate, but she's not involved with social media, her website is lacking. Her ability to get in contact with people is, is hard because she's so busy. It took me a year to even get her to call me and have a phone conversation with me. She's got so many things going on and no help. And my thing is—I'm not sure if she wants help or not. Because I've offered it in emails and I've offered an email. And I feel like if she really wanted it, she would have accepted it. But I feel like she's a one woman show and she likes it that way. But what she's made me realize also is that she's put herself in a box. And because she's in this box, and she's not on social media, and she's not reaching out to the larger community that now—that now is present on social media, not just in little state forums here and Yahoo and Google Forms there. We're in large groups on

social media now. She's not using the capacity to reach out to the herd of chemical sensitivity people and gather the herd to back her up.

APOLLONI: Right.

SHERRIE: So what I've been doing is—I've been for the last six-to-eight months is taking the—when I get a notification about the next meeting. And at all these meetings, what people fail to realize is they allow public comments: questions and public comments. We need to start beating that dead horse with her, because we need to start the—more of us need to start asking questions as to why? Or what? Or when? And if the ADA Access Board isn't going to help, well then what about the Department of Justice? What about the EEOC (Equal Employment Opportunity Commission)? Because at some point, for most of these people—and you see them online—are going to lose their job because they can't get proper accommodation. So this is disturbing. I'm—you know what, I'm blessed. I don't have to work. My husband is taking care of me. And whether Social Security gives me anything or not my husband is taking care of me. Like I have the biggest blessing in the world. There are ninety, probably eight percent of people like me who do not have this, and are in fear of losing their job, or they're fighting for accommodation. Or they're—you know—deathly ill and, you already know, homeless.

[01:17:57]

APOLLONI: Yes.

SHERRIE: So I've been taking this information, trying to get other people to get involved. And then there's several pages—and I don't know if any of you guys are in. There's a group called COFFEE, and one that's called Access to COFFEE, which is Creation Of a Fragrance Free Environment Everywhere. They've kind of cut off people getting into groups because the people that run it are based out of Alberta, Canada, but they're older, and they don't have the spoon. And they don't want to deal with all the stuff that's in the larger group: like people asking the repetitive, mundane questions when they can just (search) the threads and find the discussion prior. They don't want to have to man the ship for as much as it takes. And I understand that. But you know, there are a few groups where I've been adamant about trying to get people to write letters, because I'm big on, "If companies don't hear from us, then they don't know." And albeit they may not care. If we continue to write them and we write them a number, somebody's going to—we're planting the seed of thought if anything. And the best we can do is plant the seed of thought and hope that somebody cares at some point, or somebody takes action.

So my thing is, is if we plant the seed of thought—because we wrote like say Target. I wrote to Target about their bathroom because of the air freshener. Well, they're (like), "It's a corporate thing." Well I wrote corporate and I didn't get anything back. You know, well I wrote corporate, or I sent him a Facebook post and said, "Oh, well, you need to— you need to call this number." Jesus Christ, I don't want to call some number or have a conversation with some oblivious customer service rep on the phone. I want to send somebody an email, I want to send a CEO email, or I want to write them a letter. I've been posting things, you know, trying to get people to, "Ok let's write in groups," like everybody, write Whole Foods and say, "It's not okay to have

scented soap by the produce section because I can't shop your produce section because it stinks like Bed Bath and Beyond. Like this is a problem. You're supposed to be Whole Foods. You're supposed to be better about health. You're supposed to—" you know what I mean?

So we're not going to be heard unless we come out in numbers. So I've been pushing for people to write companies, whether it's: I dug up corporate information, here's the mailing address, you know. And I know a lot of people are like, "I don't want to write a letter and print it or write a letter and put it in the mail." But it's like, you know, what, email can easily be deleted. I want somebody to get something in the mail that they have to open, that they have to read. And then they have to go, "Oh, look, we got an actual letter from somebody. I need to get this to so and so," you know. Maybe that receptionist or whoever opens the mail is going to be like, "Oh god, this is stupid." Chapter Thirteen. Throw it in the garbage, maybe. But maybe, just maybe, if she got ten or twenty of those letters, she'd be like, "Okay, something's going on. Let me get this to somebody and they can do something about it." Now, granted, I think that's been like beating a dead horse. Because I'm doing this, and I'm putting it out there saying, "Hey look, I wrote cold, and this is my response. I think more people need to write cold. Here's corporate, here's the contact page. Here's this, here's that." So I've been doing that a lot, and not getting a whole lot of response.

APOLLONI: You mean from other folks in the group?

[01:21:20]

SHERRIE: From other people. Because a lot of people, what you'll notice is they want to complain about the situation. They want other people to commiserate with them. But they don't want to act.

APOLLONI: Right.

SHERRIE: So my thing is, you can complain until you're blue in the face, but you're complaining. You're preaching to the choir, and the choir can't help you out unless you tell us something. So when I see somebody complaining about a job or company, the first thing I say is, "Well, who do you work for? And I have some pamphlets. I can mail to your boss or I'm not opposed to printing off the Job Accommodation Network, accommodation pamphlets, and mailing it to them." And I might say, "Hey, you can do this yourself. Just put the return address to the Department of Labor. They don't even have to know it's you." I mean, seriously, people take—you know, I mean like seriously. I've made these suggestions but I don't have problems with printing this stuff and mailing it for you guys to help you out. But you're just beating a dead horse if you don't, one, want us to help you out or two, you only want us to commiserate with you. So that's one way I've been trying to get involved and actually trying to get to stir the masses.

The other thing is keeping track of the Access Board meetings so people can make comments. I did one public comment. I was going to do a question when I did the EEOC—when they had the EEOC lawyers present last month—but I actually registered for a question and then I forgot and went off and gallivanted for the day and forgot I was going to be on this conference call. So I

screwed that up. So, my other thing is, now in my head over the weekend, as I watched Dr. Lisa Nagy videos. Have you guys watched Dr. Lisa Nagy? Okay, so she is a doctor who got chemical sensitivities, extremely bad. I'm talking worse than me. She was also EMF (Electromagnetic Field). And now that she's gotten better, she's not just an advocate, but she's going around doing speaking engagements. And she has done a lot of videos. It would be probably helpful for you guys to watch, maybe a few of her videos.

But I have—since I've watched her videos—and she did talk about advocacy and legislative measures. And one of the things she said that part of her—I don't know if she has a foundation or group out of her practice in New England—but she did state how she is trying to work on getting the medical community to recognize it, to try and raise awareness, with you know, politicians. I'm thinking since she's the only one that I currently know of that's active, that I'm going to try to connect with her and see what I can do as somebody that—I'm not mobile. I don't want to really go to speaking engagements per se. But if there's administrative stuff and/or website stuff and/or getting information disseminated out to the MCS community, I can do that for her. Because I want to be involved because I feel like there's—we need a movement.

APOLLONI: Yes, yes.

[01:25:00]

SHERRIE: You know, we need a march where—unfortunately we all can't march—but we need a march—

APOLLONI: A virtual march—

SHERRIE: —and I'm trying to find an avenue of where I can get involved, because I don't want to start with myself because there's others going on. It's just a matter of collaborating and getting people to come together. Because there are doctors that have had chemical sensitivity. Dr. Ann McCampbell had it and the reason I found her is because she was on the board of a woman that ran the Ohio Network for (the) Chemically Injured (ONFCI), Toni Temple—but unfortunately, Tony Temple died in 2016. So as I'm trying to get involved with people who are part of this—this movement—and I'm more vocal and/or public manner, things, you know, things are falling to the wayside. A lot of the older groups, like (unclear) and the Chemical Sensitivity Foundation (CSF), Awareness or Friends, you know.

These websites and these people are—they mean well, they've got great information for you. But it's hard; it's pushing for legislation. And working with legislators and pushing people to write companies or petition. They're not involved. They're not doing all this, and we need advocacy. We need change. And so like Ann McCampbell was one. She's a doctor. She had chemical sensitivities. She's got a great website, and she does a little pamphlet that you can buy—you know, of course, and I'm thinking, "I could have printed this up myself," but I bought it anyway. But I bought it anyway, because I feel the need to support people who, you know, are for some way shape or form, working towards the cause whether it's educating people or whatever. You know, when you have doctors that have it, their information is very pertinent to the cause because other doctors aren't going to look at them like they're a psych patient.

[01:27:02]

APOLLONI: Of course, yes.

SHERRIE: So they're needed in this movement. They're essential to this movement. So whatever they have or do is essential. She's not into advocating. She really wants nothing to do with it. She doesn't want anything to do with working with other foundations, associations, or doctors. She just wants to exist because she's older now. And she's willing to do this pamphlet, and she's willing to—I think she's willing to do, like, testimonies for you if you are having Social Security cases. She's doing things that she can do, I guess, to make an income and have a productive life too. But she's not working on advocacy stuff. So, there are doctors out there. So my next step is just get a hold of Dr. Nagy, and see if I can get involved with her effort. So, that's my extent of advocacy, and I do extensive letter writing. I seriously will shoot off emails and letters every week. Whether it's to Target or Kohl's or Whole Foods. Or just taking pamphlets and mailing them to—whether it's—I went to a spine doctor a few weeks ago, and I needed to educate them on some issues. So it's sent emails and pamphlets. So I try to stay up on doing something.

APOLLONI: Yes. Well, great. Thank you. So I think those are all of the questions that we have for now. Christine, did you have anything you wanted to (unclear)? Is there anything that we haven't talked about, or that you would like to get on the record that you're—that you think is an important part of your story? We can also—

SHERRIE: I'm not sure if you are focusing on limitation, and what each person's limitations are in life in general—

APOLLONI: Yes, yes.

SHERRIE: —because some are worse off than others. Some have—it's like an onion. There's layers.

APOLLONI: Right.

SHERRIE: And we—some have different levels. So what one may be able to do, others may not. You know, there's a lot that don't venture outside of their home. They dare not go into a box store, like a Walmart or a Target. Most can barely go into the grocery store, you know. Stay clear of the laundry aisles. So, they're lucky if they can even venture outside of their home. I can still venture outside of my home. I'm not a universal reactor.

[01:29:49]

APOLLONI: Right.

SHERRIE: So I can still, I will go to the grocery store. Albeit I'll stay very, very clear of the laundry aisle. I make my daughter go up and down the aisle because my daughter goes—my

youngest daughter still at home—so I make her go everywhere with me, especially stores. And of course, if I need to use the public bathroom, that's an issue. I have to have a mask on. So I have limitations but it's not gotten to the point where I cannot go into—definitely cannot go into a Target. Do I want to be there long? Or do I want to be here all day? Or do I want to go into a Walmart? No. I cannot go into a Dollar General, like there are definitely stores I cannot go into. Dollar Generals—

APOLLONI: Interesting--

SHERRIE: —I can smell them from the road. They smell like a Febreze bomb. I wouldn't go in there even if I could tolerate it.

APOLLONI: Right—

SHERRIE: I don't even want my husband going in there. I'm like, "Please stop going into that store. It's just— it's unnecessary. Go into a Walmart. Go into a—I don't care. A Dollar—Dollar store. Just don't go into those." But I don't have the extreme sensitivities to the point where I can't—I can take certain precautions to go certain places. Now do I want to be in them? No, I don't like to go, obviously, unless I need something. But I can still try to go over like family members' houses as long as I know they don't: use air fresheners and Gain, and didn't recently mop with the Swiffer, spray Lysol or stuff like that. If I get exposed to something or I sense something, I can remove myself from the situation and mitigate it.

APOLLONI: Right—

[01:31:38]

SHERRIE: But I don't like—I do have issues with being out in my yard. And somebody using, like Gain and fabric scent, whatever. If it hits me, I will get—start to feel nauseated. And I have to remove myself from the situation, which is come inside the house until that has cleared. Because I have, albeit, I have some limitations, I'm not homebound.

APOLLONI: Yes. And this year, the home that you live in, is that—how do you make sure that your home itself stays safe for you? Like, did you—

SHERRIE: Well, there are—we have to set limitations on people, and we have to be protective of those limitations. You know, we have to—and I know I beat this dead horse but it's—and I say that to people online too—like you got to stand your ground.

APOLLONI: Yes.

SHERRIE: Like if somebody comes to your house, and they know you have these issues, but yet they don't get it or nor do they want to, well then, coming in the house is not an option.

APOLLONI: Right.

SHERRIE: It's just like that. Or if it's a contractor, and you know, unfortunately, I can say, "Oh well, no cologne, no heavily fragranced this," nobody's going to—you're going to have to let them in to fix it, because they're going to have to do it, you know, fix the toilet, fix the tub. And they're going to have, you know, unfortunately they're—whatever soap their wife uses—they don't care. And whatever body wash, you know—they're only going to understand and accommodate you so much. So, I try to just educate and say, "Hey, like if contractors are coming to my house, can you tell the contractors, no cologne: no colognes, no sprays, no whatever." I have to mitigate my house at that point, which is: open windows, one fan. Because if that lingers in my house—if whatever they—the Gain or the Axe body wash or whatever lingers in my house—it will make me nauseated. So what it is, is I just—my house is my safe haven. There are no cleaning products per se. There are no body products with fragrance in them. And there's no one that really comes in here that lives here that uses this stuff. So it's me, my husband, and my daughter—

APOLLONI: And then—oh sorry. Go ahead.

SHERRIE: Go ahead.

APOLLONI: Oh, I was going to just ask, the building itself of your home—did you build your house? Or did you just find a house—

[01:34:18]

SHERRIE: I did not build the house because obviously, I already had a new house. And that's what tipped the bucket.

APOLLONI: Right.

SHERRIE: And knowing that that's a problem, and to build something to suit this need would be so astronomically expensive. We went with an older home. So, we went with a 1972 brick ranch that only had one owner. And so these old people went into a nursing home, it still has that air of 1970s to it. It does have carpet, but it wasn't new carpet. It was the very plush, baby blue. Maybe it was the nineties that they got it? But you could tell that these people probably didn't have teenagers in the last twenty years, and probably didn't have pets; the carpet was impeccable. Now, granted, the countertop was a new laminate and they threw some vinyl flooring in the kitchen. And that was an issue for me at first. I knew the bulk of the house was so old, but well taken care of and didn't have these elaborate updates. Like there wasn't a kitchen full of new cabinets which you would have been MDF board (Medium-Density Fiberboard). That would have been a real big problem. There wasn't new carpet down. Now do I want to deal with this old carpet? Not really. We're replacing one room at a time with tile. So I take a lot of precautions.

In addition to when we have things done, I make sure I go into a non-toxic route. You know, I know not to deal with fiberglass outside door because it has formaldehyde. I do a seal. The tile. You know, getting—I have a guy that's doing a special build on a new vanity, bathroom vanity for me. But the best thing I can do with my home is using it to educate people. And that's with

signs on my door. So signs that say, “This is a fragrance-free home, which means no fragrances, no lotions,” this, that, and the other. In addition to—I have another sign that says, “No toxic laundry products whatsoever. And that means your Gain.” So when people come to the door—whether it's the mail, you know, like FedEx or UPS, or if it’s the local Latter Day Saint church people wanting to talk, you know—I give them a moment to look at that. And I slowly open the door and say, “You need to stay back, because you’ve read this right?” And then they stand back. And then I'm like, you know, “What do you need? What do you want?” Whatever.

People know by seeing that that it's not an option to come in my home. And even the contractors that I know have to come in my home, they have to sit at the door and look at that first. And then they have to sit here and go, “Oh God, is this lady going to let me in her house, what are we going to do?” You know, and then I address it at the door with my mask on. You know, so that's my home, it is my safe haven. We don't really open the windows a lot, except for on certain days at certain times when I know there's not laundry going on. And I know that the mosquito fogger wasn’t—didn't come by the day, the night before, because that is something they do in the south. And a lot of the larger cities—albeit not in the small, country, poorer town—but it's something that they do more in the cities that have got a lot more growth and seem to be trying to keep up with the Joneses. You know, so it is something that they don't realize is ineffective and unnecessary. Because—until it's like glyphosate and people—there's more research, which there's already a lot of research, and I don't understand this—it's never going to stop until somebody fights it. But it is my safe haven. My home is. And those are the precautions I take.

[01:38:42]

APOLLONI: Yes. Okay, is there—

SHERRIE: I can’t think of anything else.

APOLLONI: —anything else? Well, thank you so much. It's been really great hearing the story from you. And you're a great interviewee because you talk so freely and so, it makes my job really, really easy.

[01:42:35] (End of April 29, 2019 interview)