

Oral History with Ray Humphrey

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Interview with Ray Humphrey

SESSION 1 (3/24/2020)

[00:00:00]

HUMPHREY: We started social distancing really early, just because we have friends and family overseas, in Milan and around Italy. So, it's hard to say because I've been home for quite a bit longer than most of the folks here.

YIU: Yeah. Okay. It seems like we can actually record now. Thank you, Melissa.

JAMERO: Great.

HUMPHREY: Cool. Is it working now?

YIU: Yeah, it is working. Can you see the recording on the top left corner?

HUMPHREY: Yes. Yeah, there we go. Okay.

YIU: So, it's recording now, and I also have my physical recorder as a backup.

HUMPHREY: Fantastic.

YIU: It sounds like you're really in the hotspot of it all.

[00:00:50]

HUMPHREY: Well, as far as like the local infections, that's what it sounds like. We're geographically right next to the two confirmed cases. I haven't checked today but the last I checked, it had gone up to like 24 confirmed cases. I have friends in the healthcare industry saying through the grapevine that we're going to hear about a lot more confirmed in the city as well pretty soon.

YIU: It sounds like everywhere in the US (cities), people are just scrambling for supplies and goods.

HUMPHREY: Yeah

YIU: It's not looking great.

HUMPHREY: It's not looking great. Like I said, prior to the recording started, we started social distancing, and quarantining a lot about a week before the official call. Thankfully, we were well poised. St. Louis has a pretty remarkable radical activist community that started mobilizing mutual aid efforts quickly. We've been really fortunate that we've had people who are able to go purchase groceries and stuff for us so we can maintain quarantine.

YIU: Wow, that's wonderful. I hope that we can talk about some of that today as well.

HUMPHREY: Yeah, so I imagine you have some questions. I don't know how this is going to work so I'm just looking forward to being support(ive).

YIU: Thank you so much for making the time for us today, Ray. Before we start, do you have any questions for me about how this interview goes, the kinds of questions that I'll ask, and questions about perhaps using a pseudonym and anything like that?

[00:02:28]

HUMPHREY: I think they will emerge because I've spoken with a couple people and I've read through, the information they gave me about the project. I don't require a pseudonym. I'm just very curious about how you're going to be conducting the interview. I will just put the caveat on it that I'm in long-term recovery and part of it is a neurological recovery, so I will say that I tend to switch words right now and I'm having trouble with recall. I'll just put that out there. If I skip track a little bit, it's partially that.

YIU: Great, thank you. A large part of this interview is making it the most comfortable for you, so I want to put it out there that if we want to do it at 20 minute intervals and take breaks in between throughout the day, that's completely fine as well. I have nothing to do up until 3 PM.

Another way that we can do this, if you feel more comfortable, is to schedule different calls throughout the week or whenever you're free. I have also done it in a way where I do asynchronous interviews with one of my interviewees because of their attention span that is limited with the illness. So, you can certainly do that as well where I pre-record my questions and you can record your answers to those questions and we would be in conversation.

HUMPHREY: Okay, I think we can just kind of see how this goes.

YIU: Perfect.

HUMPHREY: Yeah.

YIU: Okay. So, if at any point I ask any questions that you feel as though you don't want to answer, or you can't think of an answer right now, you can certainly just let me know.

HUMPHREY: Okay, great.

YIU: Today is March 24th, 2020. I'm here with Ray Humphrey and this is Nic Yiu with the UCLA Center for the Study of Women. We're beginning our oral history interview for the Chemical Entanglements Project. Ray, can I ask when and where you were born?

HUMPHREY: Here in St. Louis, actually, in 1974.

YIU: Okay. Tell me a bit about your parents and your family background.

[00:05:11]

HUMPHREY: Yes, let's see. I'll start with my mom. Well, I will start with them both. My mom and dad are from a small town on the other side of the river in Illinois called Vandalia. They met there in high school, they were high school sweethearts. I'm not sure how in depth to go into any

of this, but I was born here. My mom was a nurse. My father was an army pilot. He was drafted. My parents were married. Gosh, I don't even remember when they were (divorced). I think they divorced in '75; they were married for eight years. I'm not that good at math right now. I don't know if they would have gotten married before he got drafted.

My mom was born to the town doctor. It was kind of one of these footloose towns where they weren't allowed to dance in public and incredibly racist. My grandfather's Jewish, my grandmother's also Jewish. There's a lot of layers within the Jewish community. She couldn't prove her direct, matrilineal line of Judaism so she had to convert to marry my grandfather. The town that my mom grew up in—she has dark hair, dark eyes, dark skin, and was really treated kind of poorly there. And my dad was sort of the big popular good-looking guy and they were this whatever couple and they were madly in love for, I guess, a few years and they were together for eight years total. My dad came back from Vietnam in '70.

He was a Birdog pilot, which is a reconnaissance pilot. Because he's dyslexic as well—I'm also dyslexic—he was not really good at school. He went to college, dropped out, failed miserably but made it through a semester successfully. So that, in the 70s, in the draft in Vietnam, by that point, made him eligible to become an officer through the draft. So even though he had never aspired towards it, he became an officer and led a platoon of reconnaissance pilots in Vietnam and was exposed to very high amounts of Agent Orange while there. Often times, the Birdogs would go behind the—I don't remember the name of the planes that actually you know, would let out the gases, the DDT gases—so he was exposed to that as well as other stuff. And when he came back from Vietnam, he was definitely addicted to drugs. My mom's mom is also an addict, but my mom is one of these just—she's an incredibly sweet person. She's got two sisters. I kind of joke that I was raised by a three headed mom because it's the three sisters who are just best friends, Jane, Jill and (JC). They are all Joshua's children. The three J's. Yeah, so, but my mom's life was also pretty hard. Her dad, he's Jewish, was tolerated in town because he was the doctor. My grandmother has migraine disorder. He got her kind of hooked on some heavy opiates and barbiturates while he was having an affair with his secretary and disowned my family when my mom was fourteen.

Needless to say, both of my parents were really lovely, charming, wonderful people and they were subjected to these very traumatized families. My dad's family is Irish working class, lots of alcoholism and drug addiction. And then they met, got married. My mom came to nursing school here in St. Louis. I was birthed by the same doctor that birthed her and all of my cousins and siblings, and then she moved around with him from base to base. Yeah, so that's who they were when I was born.

[00:09:50]

YIU: Right. That's wonderful.

HUMPHREY: And then they divorced.

YIU: Yeah. I mean, that's a really clear and wonderful narrative that you just laid out for me. I think that details are really important to understanding your story and your history as a person.

So, you mentioned that your father was a pilot and he was drafted. You were born in St. Louis. Did you grow up in St. Louis?

HUMPHREY: I did. I grew up in St. Louis in a town called University City. I was actually born first in South City, St. Louis, which is notoriously very racist working-class white area. I was born deaf. I have 15% hearing in one ear, which is an important detail.

Two very significant parts of that first year of my life was that on more than one occasion bricks were thrown through our window that said, “Die, Jews. die.” Once in response to my mother lighting the candles and putting them in the window for Hanukkah. And you know, we kept Shabbat and all this. My mom and dad were also really struggling. My father's an alcoholic. And my mom was planning on getting a divorce when I was conceived. And then they made it about eight months before the divorce happened.

My mom decided to move us from the city into a neighborhood called University City. It's a small town that's very Jewish so she felt this is going to be safe for us as a practicing Jewish family. And you know, finding out that she was going to become a single parent, it was really important to her to raise us within the synagogue. We moved to University City when I was three, and at that time, I was still deaf. Just by nature of everything that was going on, they weren't really picking up on what was happening with me. So, I got medical attention quite a bit later than I probably should have. A woman across the street from us was my babysitter, but she was deaf in one ear, so she really helped me be really adaptive. She really helped me learn how to read lips and feel for vibrations and things like that. We lived in University City. My mom is a single parent. She's a nurse, so she was working six, seven days sometimes. My aunts would come take care of us when they could. My father was unfortunately that really typical story. He would show up some weekends and wouldn't show up other weekends.

YIU: I see.

[00:12:32]

HUMPHREY: It was pretty tough. I mean I was definitely raised in a pack of kids. I was an '80s latchkey kid in University City. I think a lot of the stuff that I now understand as being sensory processing disorder, possibly spectrum stuff, was apparent then but there was really nobody talking about it in the '80s. My mom is just at work, “She's doing the best she could” kind of thing, you know? So, I grew up kind of with a bunch of other kids raising ourselves. (I was) really sensitive as a kid: I would arrange my toys and do a lot of self-soothing behaviors.

YIU: Wow.

HUMPHREY: That's what my childhood was like.

YIU: Yeah. So, you did not have siblings, but you were in the neighborhood—

HUMPHREY: I did.

YIU: Oh, you did?

HUMPHREY: I have an older brother, Seth.

YIU: How much older is he?

HUMPHREY: Three and a half years.

YIU: Wow. So, it was mainly you and your brother growing up because you said that your mother was a nurse?

HUMPHREY: Yeah, so she's working long hours and at some point, was in bed a lot, depressed. She tried for a lot of years to maintain a social life, but I think she was just at work or tired most of the time.

YIU: You were saying that at three years old, you moved to University City and it was a predominantly Jewish community. Can you talk a little bit more about where you grew up? What was your home like at that time?

[00:14:16]

HUMPHREY: Sure. We ended up living in an apartment complex. So, the neighborhood that I lived in directly was on the other side of the freeway from more of the Jewish community. The synagogue and all that stuff was on the other side of the freeway. This side of the freeway we lived on was mostly single working parents, immigrant families, a lot of non-traditional families, things like that. We all had a phone tree. We would know whose parents house to go to if need be. Our babysitter was the streetlights, like “When the street lights came on, it was time to go home” kind of thing. I don't know what else to say about it other than that.

The public schools were really good, which is why my mom took us there. Synagogue was a really big part of my life every Friday and Sunday. That was also though—back then it was really interesting to consider because our synagogue got bomb threats a lot. I just remember a lot of stress, it happened three times in my childhood there. I remember it being pretty stressful, but I also remember just having so much fun with having so many kids around with so many non-traditional families. Yeah, I don't know—the public schools were good. I was really engaged in school, one of my favorite places to go was the library. I spent a lot of time with books and reading and research and dance and gymnastics. I don't know because there's a health history that goes with the chemical piece of this so I just don't know how much of that you're wanting to know as well.

YIU: Yeah, I definitely want to get into that. I'm intrigued in laying the foundation of your life history. Were there any smells that you remember with your childhood home? Do you remember?

[00:16:25]

HUMPHREY: Yeah, I mean, I'm a really sensory tactile person so that's a nice question to ask. There's this way in which—so food has always been at the center of my family. I mean we're Jewish. I just remember the one way (where) my mom and I really did get close was through our love of plants and bread and food. There would be one weekend a month where it was just her and I making bread in this furnace room that was underneath the stairs in each unit. We lived in these condos—well not condos, they're townhomes, but basically side-by-side apartments.

Underneath the stairwell would be this furnace room and we'd raise these breads and do that one Sunday out of every month. When you say smells, that's something that I deeply remember: the smell of the yeasted bread and then the sourdough.

I was actually just telling my mom about—I was asking her a question the other day. I came back to St. Louis recently. I actually live in the third-floor apartment of my mom's now home where she lived for 20 years. I live in the third-floor apartment. We were just talking about this, the other day, that she always had this huge jar of brandied peaches. This was in the '70s and '80s, (and) apparently, it's sort of our sourdough breads now. Or kombucha, I should say more rightly. They have these jars that they will feed off the peaches, brandied peaches—they're basically making hooch. I just remember this jar of peaches and just was so grossed out by it, but my mom took such joy tending to this thing. But I was just saying to her the other day how that weird jar of peaches was this silent relative that went from refrigerator top to refrigerator top to refrigerator top wherever we lived.

YIU: Is it still around — the brandied peaches?

HUMPHREY: No. Apparently, my family had an apocalyptic —like a historically bad time, the Dark Age of the 90s, and it died during that time. She said, "Oh, God, just like everything else in that kitchen got destroyed, so did my brandied peaches;" so we were just talking about (how) maybe she should bring it back.

YIU: Yeah, to start a new relative on your new fridge. So besides the brandied peaches, do you remember any cleaning products being used or any rituals of cleaning on different days that you remember from your childhood?

HUMPHREY: Yeah, I mean, we grew up in the '80s, so it was still Pine-Sol, ammonia. I remember one time I accidentally blended ammonia and bleach. It was horrible.

YIU: Oh no.

[00:19:14]

HUMPHREY: Yeah, I was six or seven. No one was around, and I put them together. It was a weird explosion of gases. It was horrible. My mom and dad in the '70s and early '80s, they were the first vegetarians—Diet for a Small Planet of their generation. I also remember them trying to be as 'natural' as possible. Back then it would have been things Pine Sol and just ammonia and bleach. Because my mom worked at the hospital, we had a lot of hypoallergenic tapes and things like that for when you had an injury, and I was very allergic to all of that. I was very allergic to a lot of the soaps that were out back then like, Gee, Your Hair Smells Terrific, or whatever. I loved the name of it, but I had really bad dermatitis. I just loved the bottle, I (would) do little, Gee, Your Hair Smells Terrific commercials with it, but it always irritated my skin. Even when I was a kid, I really needed to have things as natural as possible. When they came out with things like Scrubbing Bubbles, and all of that, I would break out in just horrible rashes: dermatitis, eczema. My mom had said ever since I was a kid, she had to use very gentle soaps.

YIU: When you were young, you broke out in hives when your mother used Scrubbing Bubbles?

HUMPHREY: Like dermatitis almost. If I would take a bath in the tub afterwards, my skin would just get so dry, and I get these patches on my forearms still to this day.

YIU: From cleaning chemicals?

HUMPHREY: Yeah, from cleaning products. Especially anything perfumed, like the ‘clean’ smells and even with our foods. When she started transitioning out of eating more vegetarian foods, I started getting really sick all the time; my brother didn't seem to get as sick from the foods. But once we started eating more convenience food or takeout food or kind of packaged foods, I was having all kinds of irritable bowel or my stomach would get really bloated and painful acidity and all of that. So, I started showing high sensitivity to food preservatives pretty early on, but I didn't start coming into contact with any of them till I was about six or seven, eight-ish.

YIU: Oh okay. What's the first time that you remember experiencing food sensitivity or fragrance exposure symptoms?

HUMPHREY: School age, as soon as I started going out from home into the world a little bit more. I just remember the smell of the chemicals at school, like the cleaning chemicals and the certain cleaning chemicals at the hospital. My mom worked at the hospital so I spent a lot of time there when I became school age: five, six-ish like preschool, kindergarten. I would sometimes get headaches but when you're that age, everybody's like, “No, no, you're too young. You don't get headaches.” I don't know. But yeah, the smells were just always too strong, and they hurt my head and sometimes it gave me a stomachache.

YIU: Oh, so you were quite dismissed when you were younger?

HUMPHREY: Absolutely. And I think a lot of it has to do with how busy the family was; but also back then we just weren't talking about children's sensitivities the way we do now.

YIU: I see. So what was the first time that you remember linking sensitivity or any symptoms to fragrance?

[00:23:38]

HUMPHREY: My mom and aunt all did, I think, when I was an infant. That part because it was just so clear when they would wash my baby clothes (with) something that was scented, or perfumed, so they had to just go—so I think that they kind of figured that out when I was really small. And then just as new products were being released to the market or whatever, and I would have a reaction. But I think that the fragrance thing was pretty early on.

YIU: And so did they make any sort of connection to why that may be? Did they seek medical opinions? Or did they simply just switch the product?

HUMPHREY: Actually, the product just kind of switched. We're just, “Oh, you're, you know, sensitive,” and I think it kind of turned into a narrative of just how sensitive I was, more than

anything. The only time that they started to look in medically to things is when behavioral stuff was showing up. And so they're just trying to figure out why I wasn't seeming to progress in certain ways, so they went and had my ears looked at a little bit more closely. It turns out that I had blockage and I was having, you know, painful ear infections ever since I was a toddler, so it didn't really make sense that they hadn't checked sooner but—And then you know, just later, I'm trying to even think anytime that they did start paying attention to sensitivity is usually because of behavioral stuff coming up, and I don't know that that correlation was made.

YIU: I see. So, what you're saying is your family was very busy so that your illness wasn't quite addressed at a young age. How was your illness perceived in your family other than that? Could you tell me more?

HUMPHREY: Well, it's sort of like, “Okay, so you're sensitive, you have allergies; you were deaf so you got to take all of your medicine.” I was mega-dosed with antibiotics. Every time I have a heart mitral valve prolapse as well, and I'm prone to tachycardia and things like that. So they would say, “Okay, well, we're gonna make sure that your heart is okay and you're so sensitive to everything, you get sick all the time, then we're just going to megadose you with antibiotics. We're going to throw allergy pills at it.” My mom was also a nurse in the western paradigm so there was definitely the honey tea if you had a sore throat but usually it was just “throw an over-the-counter at it and if it got bad, go to the doctor.”

YIU: Okay, so pretty reliant on doctors' opinions when it's serious. Do you remember going to the doctor for the first time about your sensitivity or illnesses?

[00:26:32]

HUMPHREY: I don't know if I ever went about it. I mean, I remember going for my ears. I remember going for when I started having migraines and stomach aches, but I don't ever remember being tested for sensitivities, or allergies or immunology or anything like that.

YIU: Okay, can you tell me more about the first time you made the connection between your symptoms and fragrances or a sensitivity?

HUMPHREY: First time I did? I mean, consciously or unconsciously, I'm not sure. The age like seven or eight is what's like really standing out for me. I consciously was like, “Oh, yeah, that's too much; it gave me a headache,” and it was a perfume that was popular at the time, Charlie.

YIU: And you just remembered this didn't feel right?

HUMPHREY: Yeah

YIU: I see. And so how did you first discover that this is perhaps chemical sensitivity?

[00:27:46]

HUMPHREY: Well, you know, I think it really started. I mean, because I can only speak to what I'm conscious of, because I was so young when all the symptoms started showing up, so who knows what the adults were talking about? My father, I said, was a vet and around the age

of eight or nine, I started finding his stuff from the war around our house. When I would see him, I would take it to him and then apparently, he was taking that to his therapist. He had got hooked up with the VA and then found out that there was a lot of chemical sensitivity from DDT and there were these symptoms that people were getting with regularity that were exposed to Agent Orange. We started talking about that when I was eight or nine because my brother and I would get this (feeling) with, what I now know is called, chloracne. At the time, we just didn't know this. They're like little pustules on the palm of my hands and feet. It would happen twice, two or three times a year? My brother would have it and then sure enough, if we saw my dad during the time or heard from him at that time, he would also have had it at the same time. When he started going and connecting with mental health professionals at the VA, and then health professionals at the VA, they started talking about this correlation. Then he started getting involved in veterans activism and veteran support groups and started getting really into activism around Agent Orange (and) DDT. So, I would say probably around that time was when I was starting to hear about chemical sensitivity and illness and the link to these (experiences). At the time, I didn't think "Oh fragrance is involved with that." I just knew that I had chemical illness.

YIU: I see. You said that your father returned from Vietnam in the 70s, is that right?

HUMPHREY: Yeah, he came home and I think he came home '69 or '70. I think his tour of duty was in the year of 1969 so just before the war was over. Unfortunately, he was like in Laos and Cambodia when he "wasn't supposed to be," so he was actually exposed to a lot of shit that just later didn't really find out.

YIU: Has he ever since talked to you about it because you did say he's quite a large veteran activist?

HUMPHREY: He was—yeah. He died three years ago. That was actually when I started to have a real relationship with him. He always adored me and was so sweet to me, and I was his favorite kind of thing. My brother was my mom's favorite. It just is how families are. But he just wasn't around too much. But when he started going to see a therapist and all this, and I was bringing him the stuff from our house, it started to—we just started to spend more time with each other more consistently. So I started joining him too, on these rallies on the weekends for—he would go speak about MIA, POW issues as well as Agent Orange issues and just kind of hidden agendas and hidden health issues with veterans; so that actually ended being a really big part of kind of mid- to late- school age for me.

YIU: I see and so when did you start talking to your father about Agent Orange? You mentioned that mid- to late- school age—can you give me an approximate year?

HUMPHREY: This is where my dyslexia starts to scramble things up a little bit, especially right now—I have a bit of a headache. I was born in '74, sort of in 1983, '84?

YIU: I see. And did you get involved in these activist projects?

[00:31:50]

HUMPHREY: Yeah, yeah, it was—I would definitely say that, that was my beginning as an activist. I mean, I was already drawn as a younger person just because I spent so much time at the library towards revolutionaries and things like that, but I just thought it was cool. I did my first rally as I would say as an activist when I was ten and I was consciously choosing to, you know, make a sign and say a thing and speak out for my experience of my family's (being) impact(ed) by Agent Orange.

YIU: Can you tell me more about that?

HUMPHREY: About that particular—Well, I don't know exactly like what happened that first time, but I do know that I started talking with folks. I started talking with folks. They would set up at Scott Air Force Base out here; other, like motorcycle rallies or plane rallies or different state fairs—and they would set up a booth and educate people about the POW, MIA situations because, at that time, they were trying to get the government to uncover that there were still a lot of men there. Alongside that, I was just talking about the kind of layers of injustice, including Agent Orange. So, I remember handing out flyers and talking to people and saying, “That's my dad. This is an experience we've had,” and wearing a T-shirt and all that I think—but I could just be conflating a lot of memories from those years, that it was at Scott Air Force Base, but I don't know. I mean, I was there four or five times, in addition to other places. I'm doing marches and they organize a Traveling Wall Memorial thing here, and I wrote a poem that went with the Traveling Wall that ended up in the Smithsonian, which was a big deal in our family. I was eleven or twelve.

YIU: Wow, that's amazing.

HUMPHREY: Yes. It was a really big part of that part of my life for sure.

YIU: Yeah, so tell me more about how the exposure of Agent Orange vis-a-vis the materials that your father brought, kind of, inaugurated your discovery of your chemical illness?

[00:34:20]

HUMPHREY: Well, we started to make sense of just the connections. Then it was clear. My stepmother and mother both ended up with the same kind of fibroids, and we found out that that was from my father's sperm. Then we find out that my brother and I, both are getting these (inaudible). We were eight or nine years old when we were all like, “Oh, my gosh, we're all getting this same rash at the same time.” It was just in the conversations around the dinner table, an understanding. I don't know, as far as the materials, I think it's just in the conversation.

YIU: I see. So, in this conversation, you discovered that Agent Orange is the cause of your illness. How was that addressed? Did you all ever bring it up for doctors? Did Veterans Affairs ever address that issue for your father, for example?

HUMPHREY: It was one of these things. On mine and my brother's side of it as a kid, it was like, “Oh, well, that explains why you have so many allergies. Maybe in the 30 or 40 years, when it's all out of everyone's fatty tissues it won't be a problem anymore,” which we know is not the case.

But my dad just kept pushing for, pushing for, pushing for, and then finally got—I think it was 30 or 40, I can't remember exactly the years, it's not going to come to me right now, so I'm not gonna look for it. But it was, whatever the amount of years, we know that DDT stays in your fatty tissue, there was a statement that came out, offering an apology and saying, “If you have one of these types of midline deformities, then we're going to say we're sorry and do something about it.” But when you're kind of in the end, where we were, they just said “You can't prove it was from DDT, sorry.” So that was kind of that, you just kind of deal with it.

I've been just every five to seven years longer since, just been keeping really curious about it, because there's a lot of ways that I have experiences and my brother have experiences that are so different than everybody else in our family that it just can't be overlooked—the potential relationship. So we just learned recently that it was more than likely a genetic switch kind of thing; but all of those years it was just sort of like, “Oh, well, that explains why you're so sensitive and maybe you won't be as sensitive once that it's out of your fatty tissues or whatever.”

YIU: And so how did you discover the connection to the fatty tissues and how other than the statement, was it via—?

HUMPHREY: —Research. And doing research and reading and, you know, veterans talking to veterans activist talking to activists, kind of the way that we do—we educate each other through sharing resources, and you know—

YIU: And so where do you share these resources? And how did you come to find these networks?

[00:37:27]

HUMPHREY: Well, a lot of it, for my father, was through the Missouri Vietnam Veterans Associations. He's also a biker, so he found this biker group that was all Missouri veterans that would ride together and then these activist groups started forming, you know, out of these veterans' support groups, kind of the way that most activist groups do. You know, one group would have a social or an event or a potluck or you go to set up at whatever the air show, and you go meet each other and share stuff at this shows or rallies and—You know, there was a couple marches and even there, you go and you kind of meet each other and share and exchange and have conversations.

YIU: Right, so it's more of an informal social networking information network rather than one that's relying on medical opinions?

HUMPHREY: No, I mean, I think at the time, it was in the '80s so they were relying on whatever medical opinions were actually validating and actually doing research. And so it would be the same two or three pieces of research that would be distributed through those, but it wasn't—you know, a lot of it, yes, was people's experiences and it was, “Hey, we just got this, you know, piece of research from such and such,” but I was also in grade school so who those researchers were, I couldn't tell you. Yeah, I mean, it was definitely a mix, I would say, of

people's own experiences, but also whatever tiny bits of validation were there. People were really trying to put pressure on getting more research done and more validation.

YIU: As you get into adulthood, did you ever bring this up to doctors? How is this a part of your care routine with your doctors?

[00:39:21]

HUMPHREY: I'm in this question around that right now, because people have a really particular response to it when you say, "Oh, and I think there might be something to a genetic mutation from Agent Orange." They're just like, "Okay." I don't know, I just feel it's not really taken very seriously. Because I personally haven't been seen by a VA doctor or something like that. So it's a question I'm in, right now.

Especially because, you know—so a part of the reason why it's been so hard to get this interview in is because I have Lyme disease and was recently exposed to toxic mold in my home for about a year and a half. And I've just gotten very, very sick, I mean, in very frightening ways. I'm going to get pretty emotional about that. It's part of the reason why I've been in quarantine for as long as I have been. While I was trying to figure out what was going on with Lyme, I just, you know, I'm an assigned female person. I'm queer. I'm very visibly queer, and so I already am not taken very seriously by kind of mainstream medical folk—we'll just say that for this purpose. So, when I first started getting, starting to ask questions about this, I got a young intern who basically was, "Oh, this is your anxiety so you have PTSD," and dismissed it. It took three or four years for them to finally diagnose me with Lyme, and during that time, I just was asking every question, I just laid every question on the table, "Okay, I know I'm really sensitive. I know we get these rashes. I know I've had these migraines. I get these stomachaches. The chloracne has been gone for years. And now all of a sudden it's coming back." I started picking out research—I couldn't tell you right now the names; I could probably go back eventually and find them.

But, you know, about a year and a half ago before I lost as much cognition as I did, I started having a series of small seizures and things. I saw some research that was coming out saying, "There's a potential link to the kids of vets who are exposed to Agent Orange and autism spectrum disorders." And I know that as a clinician—so I work with complex trauma; I'm a therapist and I've come to really have a love for Sensory Processing Disorder because I have it, and I know how to work with it really well, so I really working with that population. I just started doing research to see if there is a possibility that some of the illness that I'm experiencing is just a stress response to too many years of not attending to these Sensory Processing Disorder needs? Is that possible? Yes and no, mostly no.

Yes, in that it is making it pretty un-liveable for me to have these reactions to mold and increasingly more reactions to foods and chemicals, even essential oils—like I can't. And you know, is that because I had an underlying sensitivity issue that may have been from Agent Orange? But now we know that if I'm on the spectrum or in the broader autism phenotype, it may also be because of that. This is where right now, I'm just really sitting in the question, because I get in this place where I've been using my body as a method of activism for a long time. I was

involved in activism locally here as well, activism in college age, and when it's my health, I'm kind of tired of that. I don't know how to bring it up. I think it's a really good question, because I just don't know if I ever really have, and when I have it, it hasn't gone well, so instead I'd say, "Okay, scratch that. Let's see what's going to actually get me seen and taken care of and taken seriously."

YIU: Of course. You said that three or four years ago—It took you three or four years to get the diagnosis of Lyme. How did you begin the process of discovering the course of that diagnosis? Or who did you go to? Can you walk me through that process?

[00:43:30]

HUMPHREY: Sure. So when I first got bit—I mean, the thing is, it's possible I've had it a couple times in my life, now that we know the symptom milieu; because again, this was back when I was a kid, it was, "Oh, you're so sensitive. You're getting sick all the time." You know, I was also crawling around and getting bit by ticks all the time, crawling around in trees and stuff. It's possible I had it when I was a kid. It's possible I got it when we lived in New York—that, I don't know for sure.

But in 2015, I was in graduate school here at UMSL (University of Missouri-St. Louis), which is a local state university. And it was the summer that Ferguson was happening and I had been going for hikes two or three times a week, you know, locally because I was so busy in school and doing my internship. I couldn't get out to the further ones that I would have preferred. I got bit by fifteen baby ticks; they just splattered on my leg, and then I brushed them all off. And a few weeks later it's—this is all just going to be deeply connected to Ferguson as well because that's my disease processes also. But I was doing Shabbat one week, and I was so fucking tired. I have never been so fucking tired. I'm taking the whole weekend off from media the whole weekend, not just night." You know, I do Shabbat and don't do media Friday night to Saturday night, and so that we could take the whole weekend off, and it ended up being the weekend that Michael Brown was murdered. And I was just devastated because this is my hometown and this has been going on for so long here. It was the reason I left was—just how incredibly racist and how incredibly xenophobic.

And so I just had a feeling that Sunday, Or Monday, I think it was Sunday or Monday and I got back online and my friend Elizabeth asked, "Did you hear what happened," and I said, "No, please catch me up." And I went out the first two days to Clayton, and it was the first two days after he died, yelling on the streets, "Listen to us, stop turning the cameras from us, listen to us." It was helping teach some younger activists how to do nonviolent, peaceful protest and how to not get arrested right off the bat? So, I was doing that for the first three days and then I was so tired. I can't even express to you how tired I was afterwards—one day of yelling was three days of just sleeping. And so I got really curious about what is happening to my body, you know, why am I so—I know this is emotional, but this is ridiculous, you know? My spine hurt, my limbs hurt, my lungs felt tight, so I went to—because I'm a student at that time in Missouri, I fell in the gap where I didn't have insurance; so the only insurance I had was my supplemental student insurance. I went to the clinic where I was interning, in the mental health section of the clinic

there actually, so thankfully, really knew everybody and they were trying to figure out why I couldn't breathe all of a sudden. I have a gluten allergy that all of a sudden seemed to be horrible, out of nowhere, just blew up, and flu-like symptoms. Mind you, this is while the whole town is just in shock. Everything is just mayhem. To be quite honest, my friends are being thrown tear gas at them. I can't go be with them; I'm helping do phone networks of (encounters with) police, making sure people are safe and making sure they're getting food and taking water to them and yet I'm still trying to figure why I'm so sick. So, the nurse said, "There's something going on with your breathing, and I want you to go get that checked out." She said, "I can't say what this is, but I'm very concerned, and I need you to go get a chest X ray." So, I thought, "Great, that's great. I'm going to do that." And then I had to figure out how to finish my internship and write my notes and everything with limiting my exposure to the office because we shared HVAC with a kiosk next door that had pizza and bagels. And my reaction to that was getting so bad that I would be in session and all of a sudden, my client asked, "Are you going to be okay?" Horrible, and mind you, this is at a client load of eighteen folks, and seventeen of them were acutely impacted by what was happening.

[00:48:11]

I just was doing the best I could with what I had. Eventually, you know, I was getting acupuncture and getting everything taken care of, as far as the increasing headaches and fatigue, and my acupuncturist said, "Honey, whatever is happening to you, we're just keeping it at bay, we have to get you into a real doctor." I waited in line at the people's clinic, and it took a really long time to be seen there. And they were just about to start getting in for chest x-rays and stuff. And then I got insurance with a new job and so I had to start over again. So this is like a year later, and then that's when I went to the internist and they said, "You have PTSD. This is clearly your anxiety—"

YIU: Wow.

[00:48:51]

HUMPHREY: "You know, you've had a really hard time because of Ferguson," which is true; but I'm just really sorry to (inaudible) me so much. But so I went and did the reading. I went to the breathing tests, and they couldn't find anything. They said, "Yeah, we don't know. This is clearly neurogenic. You have really bad migraines and you know, you should probably go see an allergist about the rashes. But let's get you into a neurologist." And then six months later, I got a phone call from the neurologist, but I never got in to see an immunologist or anything like that. By that time, my father had called me. I was starting to get migraines two and three times a week—my Sensory Processing Disorder just kicked into overdrive. I was working as a crisis clinician at the Behavioral Health Resources which actually, turns out, I'm really good at. It's really stressful. I was doing EAP calls as well as crisis intervention, suicide, suicide intervention. I also did public presentations around universal suicidality and worked with at-risk youth who presented as highly sensitive and at risk and all this. So at that time, I was working as a crisis clinician doing grief work, EAP work, and crisis work and, just all of a sudden, my palms of my hands and my wrist started getting really tight dermatitis and little tight blisters. My fingertips

started going numb a lot, and then I would just get these splitting migraines. I couldn't play sound, and I was starting to get tremors and stutters. A lot of it, we realized this, (was because of) the fluorescent lights—I had two computer screens, fluorescent lights above and then these big screens that would have a rolling display of how many calls were on queue, and that just started to really overstimulate my system. So that's again when I was just trying to get into the internist to ask, “What the fuck is going on with my system” because in that work, like if you're not in a space to talk someone off a ledge, you can't come in—It's just unethical. If you're not resourceful, you're going to do damage, and I was less and less able to be resourced for work.

During that time, my father contacted me to let me know—my father has cardiomyopathy and he had full heart failure ten years ago, fifteen years ago, and has had a defibrillator and had two scares since then. And so he called me and, for him, it was a big deal, right? He called — typical dad move. I call him and he would say, “Well, here's your stepmom,” you know? So, for him to call me and say, “Honey, I need you to know I'm scared about my health. And this is what's happening. They don't—” His heart was failing. And so because I was getting so sick and because I wasn't able to continue at work and because my lease was ... about to switch hands, I decided to take a leave of absence from work and go help my father in Portland, to get him through this surgery. That means once again having to restart healthcare because these folks out here were literally doing nothing with me. When I got to Oregon—I had actually already been in Oregon for a couple months when the neurologist from St. Louis had called—I had a remission. I was feeling okay. So, I thought, “Well, maybe I'm fine, you know,” but I still had, in my mind, the question about the migraines. Why are they so bad? My dad was just so sick that he became the focus.

After he died, I traveled up to Canada with my partner at the time, and got really sick there and came home and started a new job and got good insurance. I started going down the road again of getting tested, but then I went to Kaiser Permanente, and I don't know if you're familiar with their policy on Lyme—It's that there's no such thing as chronic Lyme. So even my doctor said, “I agree with you. And I'm curious about all these other things, but there's this way that KP does it.” Again, just hitting into walls and then just getting sicker and sicker. I later found out it was because I was being exposed to toxic mold. There was just so much acute stuff coming up that I don't know that I really got to have the attendance to any of this that I needed, but at some point, I ended up with an acupuncturist who was treating my migraines. That was the only thing I could get them to verify and validate and take care of. I had gotten into urgent care, however—I can go into that later. I had an acupuncturist who started treating me for the migraines and said, “You have Lyme.” I said, “Yes, I know.” My doctor who's a D.O., doctor of osteopathy, said: “You have Lyme but I can't diagnose it because I was told by the Head of Infectious Disease that he knows of no disease that has the milieu of symptoms you have, and he's recommended that I don't treat you for this.” So they started treating me for Lyme, the herbs that they use cause the reactions that they cause when you are having a Herx (Herxheimer) reaction.

Then finally, a year later, a year and a half later, another insurance switch again, I get into see a specialist, finally get the official diagnosis. At that point, I've had Lyme for five years and had been exposed to mold for two years and, thank God for this acupuncturist that I had in Portland.

She literally saved my life—she took it very seriously. She started talking to—there's a guy named Bob Quinn, one of his colleagues is her mentor so they all kind of came together, came up with a treatment strategy, very aggressively treated the Lyme for eighteen months and got me to a baseline. But needless to say, throughout all of that, I keep asking the question about the sensitivities and the Sensory Processing Disorder, synesthesia, and I'm still getting, you know, chloracne and really intense visual issues. It's still something that I'm very curious about; but I'm finally being treated for what I'm sick for. It's just that it's really wreaked havoc on my life and my body. I've lost my job; I had to close my practice. I've had to move three times. My partner got exposed to mold again, which creates this huge milieu and cascade of symptoms in me so yeah.

[00:56:00]

YIU: Wow, thank you for laying that down so clearly. I want to loop back to several things that you were talking about. So would you say that your interaction with medical professionals have been largely unhelpful because of the navigation system? But what I'm hearing is also with folks that are practicing acupuncture are a way that you access appropriate health care.

HUMPHREY: Yeah, I think what's happened is that, because of my ability to access health care. Quite frankly, I'm poor, I can't afford good insurance. So you get into this managed care system where they're kind of shuffling you through, and if they can't throw a pill at it, then and you know, they try to throw pills at it, and I was having reactions to all of them that none of them were working. I think at that point, you just become the difficult case.

I just feel like there's been some well-meaning people who have really wanted to help me, and I can see their faces—I couldn't tell you all their names—but they're up against a system, and that system has their policies. The CDC has old, very political stances on research, even emergent research. So I feel like they're just limited by this, you know? You have to turn this whole ship, and by the time they've even made it one click to the left, you're done. It's been many years. So I have used acupuncture and herbalism and naturopathy and bodywork and touch work—I've become a touch work trauma therapist, because it works. Especially, since I am so sensitive, it seems the subtler the approach, you know, if I can be patient with it, the better my body responds. Especially the way she was treating Lyme, my body just was building more resiliency the whole time. I trust my intuition to pick people, and I've picked some really strong clinicians, but it's been about, how can I access them. I just had to make the best of what I can when I can get it, because again, working with a big system, it's just—I don't know. It's really inefficient. And people like me fall through the cracks all the time is what it feels like.

YIU: It sounds like in your life, you've navigated multiple, different, large structural systems that (are) hard to navigate and in different experiences, you have done activist work, whether it's vis-a-vis being a crisis clinician, or someone who is an activist advocate with your father based on Agent Orange. I want to talk a little bit more about, you know, your transition of different insurance systems due to your switch of jobs as well. How is that—in terms of contracting Lyme and also discovering that toxic mold has affected your working abilities?

HUMPHREY: Can you frame that again? How is it—

YIU: How have your illness or sensitivity that has been brought on by Lyme or toxic mold shifted your work life?

[00:59:43]

HUMPHREY: Oh, okay. I think I am always an activist, even if I'm not able to be actively organizing or out in the street. Even through my personal social media, I'm always trying to educate or share. I'm not that person who'd say, "You need to blah, blah, blah." Maybe I was when I was in my twenties, but I try to always be sharing information with people and being a resource to people. I really deeply believe in the grassroots ability to support one another, so it shifted my work in that most of my work is now in those channels of people online with disabilities supporting each other. Every other Wednesday, I do a community care work online meditation—I've been doing it for six or seven months now since I had to leave my practice before.

But I have now had to leave three positions due to the level of pain and intensity of the migraines, neurological symptoms. I was starting to get welts and hives every time I would even get hot, you know, so it was just (being) sick a lot. And as a therapist, especially working with—so again, as an activist, I really chose my community of who I work with very specifically, partially for my passion, but partially for my skills. I work with mainly LGBTQ folks, a lot of trans and gender non-conforming folks. I work with highly sensitive people and folks who are kind of broader autism phenotype and other neuro-atypicalities which tends to be a lot of high sensitivity. I already work in that way but what's important to note about that is there's also a high co-occurrence of developmental trauma and complex trauma, so I kind of had to step away from regular clinical work because as a—you know, I don't know what your background is— but a big part of my work with a big portion of my client base would be to become a reparative attachment figure. And if I'm getting sick all the time, it's really inadvertently creating reinforcement of attachment (inaudible) so I really sat with this for many months and decided if "I keep getting sick and keep being unreliable, I'm going to replicate harm to my clients." So I had to step back for my own healing.

My partner at the time, thankfully, was gainfully employed, and we were figuring out ways for me to do more non-clinical work to because I have a lot of other skills. We finally got out of the house with mold. We had to, mind you, get rid of literally all of our furniture, my entire professional library, my personal library, all of my art, all of my sacred items, everything gone. Started from scratch. And then you know, that was when I started doing a little bit more mentorship for folks. And then this meditation. I also am part of the Wu communities, which is doing a lot of that kind of guidance, and I do somatic experiencing.

[01:03:11]

Since I have not been able to work full time, I've just been doing a lot of mutual aid work and a lot of donation-based facilitation work for meditation. Working with people, other chronically ill and disabled people who are homebound, have been homebound for a lot of this past two years. I'm really just having conversations about, "Okay, here's how we're re-envisioning a lot of them, just re-envisioning literally anything and everything. Do we want to present this as a course, or

do we want to present this as zine?” We just keep having these conversations and changing the constellations of our communities based off of these conversations. You know, I'm just about to go back to work. I may be able to handle five or ten clients with my level of ability, but a lot of it shifted. It became sort of a free resource hub for people. I talked at a few people's classes and I do this meditation, and I have a couple people who I do consultations with; so I'm continuing to grow my capacity and skill and, you know?

With all the time that I have and taking a lot of the somatic experiencing training that I have, and in my own work as an intuitive healer, and looking at generative somatics and community level healing kind of akin to the work of like Adrienne Maree Brown and Leah Lakshmi and Mia Mingus. Really grassroots and like, “Okay, what we've learned these last several years is that it's not about using the tools that have always been there. It's about really learning from each other, centering our experience.” And so I think I'm in that process right now of really figuring out what is my long term vocation as an activist and educator and care worker going to be, because it's just not going to be—I can't work forty hours a week anymore. I don't know when I'm going to be able to do so.

YIU: Right, and you don't need to work forty hours a week to contribute to the community either.

HUMPHREY: Exactly. I think we figured out we spend \$2,000 a month on supplements and that keeps me alive, so how do we make that? How do we pay rent? How do we stay afloat in this world, because I applied for disability and I got rejected because migraines is one of those that you have to have to do an appeal for, but as a clinician, again, I've had a lot of clients on disability and the limits on your ability to even volunteer, I would just wither. I'm an introvert but I need to be part of something; so I'm just going to keep trying to work as much as I can. I don't know what it's going to be like.

YIU: Right. So it sounds like you said that, you know, you did this evaluation and check in with yourself about what the communities have needed from you as a crisis clinician, and that, if you were getting sick all the time, it would be difficult for you to be a positive attachment figure. So does this mean that you chose to leave the job?

[01:06:13]

HUMPHREY: It was a mutual—I think things were mutually chosen. I spoke with my clients about my health very, very candidly at the time. You know, I have an ongoing consultation with other somatic and trauma informed, radical activist-therapists—and so, really worked this soil for a long time before talking to—probably not too long because it was obvious I was getting sick.

And then my supervisor at the time in Oregon, I still had to have a supervisor while I was building my practice, and really sat down with them and said, “This is what's been going on with me.” I was overt from the very beginning. I wear tinted glasses, and I kind of tremor, so I let them know by saying, “I live with disability. This is what it acts like; I need you to know that I will let you know if I'm well enough to be here. You don't have to worry about me,” because

that's the first thing people do is they want to take care of you when they find out you're disabled, and it has already been in the room.

But I had been in practice for about eighteen months, and my ability was just sliding so quickly, and so I don't know, maybe a year before I left, I said, "You know, these are the things that are happening, this is the treatment. I'm going towards treatment and the treatment can sometimes make me sicker. And so over these next several weeks, we might suspect that I'm going to be sicker. And you can choose, if you want to continue working, if you're open to the flexibility, if you're not, I have referrals." I just was having this check in—It's part of my practice anyway to do check ins with my clients pretty routinely—and so we just were checking in over the months. And as you know, at one point, I said, "I might have to go on partial leave, which means I need to make my practice smaller." And, you know, it was clear how much sicker I was getting, and some of my clients elected to leave. They said, "I'll see you for the next six weeks while I find someone else." I had one client who said, "I can't handle this. You're too important to me, and so I'm just gonna be done today." And thankfully, that was the only one that left that day. But she ended up contacting me back, and it was interesting to help process that. But yeah, it was just a collaborative process.

And at some point, it just was getting so bad, I couldn't keep my home. And we found out about the mold, and my doctor was incredibly concerned for me. I was at very high risk for heart attack which had never happened before. I was having seizures, which had never happened before; potentially, I've had heart attacks. And it was just so clear how sick I was. So we just finally set a date. I've set an arbitrary date. At one point, like in the next six weeks, this is where we'll decide if I'm going to partial or full leave. I ended up going on full leave. We're just kind of always pacing where I was, what my client need was, and making sure they were getting strong referrals and (I) passed my office on to another somatic trauma informed queer somatic therapist to kind of make sure there was still that resource available. But it was a process, probably over, I mean, the last six months was really me preparing to leave.

YIU: Wow, it sounds like a lot of back-to-back discoveries about your illness and sensitivity that have affected your work. And it sounds like your co-workers have also known your condition set alongside with your clients. Did that impact your relationship with them? What were some ways that you found accommodations while working there?

[01:09:48]

HUMPHREY: Well, I had to leave the agency I was working at to get any accommodations; so the accommodations were to have my own practice, and even that, I do through conversation. I went and spoke with some disability advocates and a voc rehab (vocational rehabilitation) professor through a professor friend of mine and, you know, kind of talked to them about how people do this? Because the accommodations that I would need. I also do all the research. I'm dyslexic, but I also have pretty severe Irlen Syndrome and photophobia. What that functionally does is, if I'm working on a system, I need it to be as uniform as possible. Otherwise, I can't transfer information from one to the next. It's part of the Irlen Syndrome, part of dyslexia. It's down to just basic uniformity of programs, which my workplace was not able to provide. I need

to have special screen protectors and certain lighting in the area where I'm doing my office notes. I need a certain limited exposure to background sounds, scents or something that wasn't too hard to get accommodated, but then I need a break—a real rest between every client; and they just couldn't do that, which is understandable as a small agency. So, I was able to do that for myself.

Thankfully, I don't know how I'd managed it because I was sick, but I was able to accommodate my own needs and sort of practice and I had fifteen clients within five or six months, so I was able to continue working. But people just kind of—I just am very clear about what I can and cannot do. You know, my email signature will include my hours that I respond to emails; my clients are very clear about that. And I have my rituals of checking that—I check every night at nine o'clock; but I am not on it from you know, nine o'clock at night to nine o'clock in the morning, and just very clear expectations. Usually about—I mean, I think by nature of the people I work with as well—that's also been an accommodation for myself and my clients: I work with people who tend to have chronic experiences and chronic sensitivities, so I kind of model how important it is to advocate for ourselves but also how difficult it can be and to kind of know when the right time is. We'll do the intakes, we do the kind of conversations, we do those first visits and say “How is this going,” and I'll be very clear: “Okay, so here are some things I want you to consider. You know, I have these disabilities and on occasion, I have to schedule last minute because migraines can trigger pretty unexpectedly sometimes, and I'm very susceptible to weather” and just have that conversation.

And my friends, you know, it was hard because I can't do a lot of the socializing and networking events that people do, because it happens at night with bright lights and in big convention halls with fluorescence and foods that I'm very allergic to. But I managed to do it by having small conversations or kind of doing these consultation groups and taking smaller opportunities, so able to kind of maintain community that way, but I'm just having to constantly advocate for myself.

[01:13:19]

YIU: It sounds like a lot of experience in learning to self-advocate, but you also have such years of experience and activism in general that's not even related to yourself. Before we move on, though, I wanted to check in and see how you're doing. It's been an hour, almost an hour and a half. How's your energy level? Do you want to maybe schedule for another call? How did this model of interview work? Would you like to think about recording as a method?

HUMPHREY: I am definitely getting tired. I'm not sure. How much more you're needing or I don't know, I know I have a tendency to get tangential so—

YIU: Oh, not at all. I think I'm really thankful for the different aspects that you're giving me because it's really important in your various aspects of life with it. It's your family life in relation to your father or working as, you know, a crisis clinician, as well as your activism (and) advocacy experience. I think I still have quite a bit of questions to ask you and if you'd like to schedule for another time, I would love that. And also if you're not free, I am also completely understanding of that too.

HUMPHREY: Well, like everybody else, I'm home, right. So I am going to be—I'm trying to organize a couple calls right now, I'm doing a little thing with friends called “Juicy Conversations”.

YIU: Oh, wow, is that a podcast?

HUMPHREY: I wish. You know, it's not really—It's a friend of mine in Milan. And so it's us here and her there; so we're gonna have a conversation during meal time together. So I'm trying to figure out what day that's going to be.

YIU: Yeah. I wish it was a podcast.

HUMPHREY: Who knows? Who knows—everybody's looking for something right now. But I will know a little better what my availability is just because I do have my weekly call next week, and then I'm trying to add this other one.

YIU: Okay. Sounds great.

[01:16:32]

HUMPHREY: Cool. Well, I'm very glad to have the opportunity. And I will say, I'm going to be very curious because, you know, as this has been going on, I still remain very curious about the exposure to Agent Orange stuff. This is all—so I'm just very curious to learn about everything that you all are finding, because I'm still trying to figure this stuff out. And I'm still—but then it also kind of doesn't matter because I'm just figuring it out. But I'm really grateful that you're doing this. And that, you know, I really was grateful to have the opportunity because my experience has been so overlooked through the system. I've managed, right? But there's a lot of people I know that haven't, so I'm just really grateful that you're doing this work; and whatever it becomes, I'll be so curious to see what it is.

YIU: Yeah. Thank you so much, Ray, for your time. This has been more than helpful. And I can't wait to talk to you tomorrow. Get some rest.

HUMPHREY: Yeah, absolutely.

(End of March 24, 2020 interview)

Interview with Ray Humphrey

SESSION 2 (3/25/2020)

[00:00:00]

YIU: Yesterday, we talked about, you know, you're basically—where you're from, how you were born. We talked a little bit about your father and the exposure to Agent Orange and I think we ended on talking about, you know, your journey of getting the Lyme diagnosis and treatment. Today, I was wondering if we can start by asking you to talk a little bit about your self-advocacy work as a patient.

[00:00:40]

HUMPHREY: Let's see—about my self-advocacy work as a patient? Well, I think a lot of it has been—firstly, my family is a medical family. My mom is a nurse, her sisters are nurses. My grandfather, although I didn't know him, was a doctor. My grandma was a nurse. So, I was really used to just the environment, I think in general, which for me is just important—just to feel comfortable somewhere. But I was comfortable enough in hospital, medical environments, to know that I didn't agree with them—how it worked—and I didn't like how they smelled. We were talking about fragrances and chemical sensitivities—I just really always felt a little bit uneasy there as well, but I was also very familiar, if that makes any sense. I think because of that, I felt able to speak up in those environments especially because, as a kid, I had gotten sick so many times.

I think because my neuro-atypicality is something that has gotten overlooked a lot. Like a lot of people on the spectrum, have this way of presenting that is either—it's a bit of a limited range—and so mine goes towards kind of flat to very animated. And I smile a lot sometimes in weird ways. It's just kind of—I recall as a kid being really, really sick and having 105 fever, but my personality was like, “Oh my gosh, this person is so—they're so upset about me being sick; I want to cheer them up.” I was smiling and I'm like, “Yeah, I'm sick. It really sucks, but you're so sad,” you know?

I realized that if I didn't speak clearly to my experience, that I was going to get misinterpreted, misread, and then later realizing (being) misinterpreted, misread to people's biases or agendas or to-do list or stress, you know? Because I just watched. I watched my mom at work, I watched the way people treated each other. It's just kind of who I am, how I am. I'm very interested in how people behave, and kind of have always looked at the math and geometry behind that which might sound strange, but if you're a systems thinker, it's something we talk about how systems—there's these kind of rules and roles of engagement. And so I just, at whatever age, figured out—I can language it now but I couldn't have language it then—that if I didn't speak very clearly to what was going on with me, people were going to take either this weird smile or very flat affect in whatever way they were going to take it: either that it was ignorant, or that I was not telling the truth or whatever their bias was. I just kind of became, you know, aware that I had to do that. But also again, I think because of my neuro-atypicality, and my ability to just speak up as part of

that, I don't know what it is—I mean, we all kind of feel compelled to speak up as I've noticed. I think that that's been the combination.

Unfortunately, because I am assigned female and I present in a particular way, I've been dismissed a lot and disregarded and I tend to—I don't know, I can't actually say what or why, but I've been overlooked so I felt “Well, I have to speak to this.” I can't rely on my mom who was kept over and over again waiting for that doctor's diagnosis to validate my experience. I can't wait for people who are really trusting the system to act quick enough because I experienced things at such a sensitive level that are unlivable for me that if I don't speak up, it's just gonna get worse or unattended to. I think that that's from—I don't know, it's the first time I've ever really thought about that.

YIU: Right, so you're talking about, you know, your ability to speak up in self-advocacy. Are there examples that you can think of where gender has played an element to your access or inaccessibility within the healthcare industry?

[00:05:16]

HUMPHREY: I mean, I'm sure there's more that I can even count because there's so many unconscious biases, and I just don't know what the other person is thinking. But I think what's glaring right now, just because it's fresh from our conversations, was when I went to go—well no, it may be my perception of gender, I don't know—but when I went to go to my first visit with insurance when I was working as a crisis counselor at the HR (human resources). I went to a local university hospital group that my mom worked for forty years; my uncle works for them, you know, whatever—family loves them. But I went in and my mom actually came with me because I was really anxious, because I had been really sick for a long time and it was very distressing. We also knew that I was going to have to sit in a waiting room with fluorescent lights on, and they've all been changed at various times over their lives, these fluorescent lights—they're all vibrating at slightly different levels which can cause me to get a migraine or tremor or stutter or whatever. She came with me, and we go and we sit down and it's this young cis man who is probably eight or nine years younger than me, and he just wouldn't—he would talk over me. He wouldn't listen to me; when my mother spoke up, he especially didn't listen to her. But the fact is: my mother is a fifty year medical professional, has an incredible amount of insight into the body, but (he) just completely disregarded everything we were saying. Then he starts chastising me about supplements and then tells me that all of these headaches and everything are because of my anxiety, and I really need to get it in check. I mean, (he was saying that) I'm taking up too much time and was like, “What is the problem? What is the problem?” It was—I just really don't feel like, if I were a man, either of his age or older, or if I had been there with my father, that he would have kept talking over us, and dismissing and going straight for: “Oh, here's the hysterical trope. That's the answer.”

Just even when I was a kid and having anxiety—not even anxiety—that's what they turned it into, anxiety. I was having a lot of discomfort in my body and having a lot of sensory activation at school and it comes up as behavioral for me. And then when I would tell them that I had these stomachaches and headaches and things like that, that wasn't attended to—It was my behavior,

you know? It was like, “You're not behaving like a little girl is supposed to. Little girls don't hit other people, little girls don't do that, little girls don't dig in the mud,” because I got mud all over my clothes and was eating these wild (inaudible) in the back lot of the playground. I had a worm and I was like “Whatever.” And so I think just—whether they're directly related or not, you see the ways that people dismiss and disregard your experience and always go towards your behavior, or your hysteria, and questioning the validity of your experience because it's not within that kind of decorum, if that makes sense.

YIU: Yes.

HUMPHREY: And I think that that's the only way I can describe it, because I've just picked up on it when I have worked. When I was at Kaiser Permanente, I recognize even there, one internist who was an older cis man was able to get a referral for me much more quickly for my PT than my own doctor, who was my doctor. My primary care physician, a young cis woman, who was—basically patted on the head and told, “No, no, now this can't actually be real. Your client is clearly—this is all in their head” so—

YIU: Which part of it was—what was she treating you for that they have described it being in your head?

[00:09:40]

HUMPHREY: The milieu of symptoms that are Lyme, basically. And then how the Lyme was causing me to—because I have migraine disorder and you know, Lyme comes with a headache for almost all of us—but because of migraines and the multi-systems kind of nature of Lyme, my immune system is already pretty jacked up as it is, so that combination from Lyme is causing all these migraines. She was kind of told, “Now, now, just treat the headaches,” and then I was taken down this road of antidepressants, anti-psychotics, anti-anxieties. They said, “It's not—there's nothing happening in her, in their actual body. It's all in their head.”

YIU: Oh, so what I'm hearing is there is a largely symptomatic and systematic dismissal of the various symptoms that your body was experiencing and is still experiencing, as what I'm hearing.

HUMPHREY: Yeah, unfortunately, pretty badly. I mean, it's not to dismiss that there has been a lot going on in my head. I mean, the neurological symptoms have been pretty distressing and my immune system is rebuilding itself pretty slowly but, yeah, I've basically lost a good portion of my vision through this. Well, we only know—we think it's a neurological thing because it's not typical blindness; it's a lot of disruptions in my visual field. I still get stutters and tremors and kind of partial seizures. You know, I'm talking to you right now and I've been navigating migraines and I just don't know what else to call it but neuro- symptoms because it's just a combination of vertigo and memory issue and recall issue and for five days straight because there's been a storm front coming through. So, it's just I mean I'm better now; I'm not at the verge of dying because of the mold toxicity, but it's taking a while.

YIU: Yeah, and, again, please let me know if you'd like to pause or take some break.

HUMPHREY: Yeah, I appreciate that.

YIU: —Or go for shorter intervals. I'm really appreciative of your energy. So it sounds like what you called neuro-symptoms and you're beginning to learn to really master the language of talking about some of the things that you experience as a patient. Did you ever bring up chemical sensitivity or anything like that with the doctors in association to Lyme, and how did they respond?

[00:12:32]

HUMPHREY: Yeah. And that's just it. I ended up getting during that time—because of things like chemical sensitivity that I was mentioning throughout all of this and how I was getting increasing sensitivities with Lyme, but I've always been sensitive to certain things, including hypoallergenic tapes and stuff like that. I brought it up, and it's one of these symptom experiences—and I'm sure I'm not alone in this where people are just kind of like, “It's a side issue as opposed to an avenue”—so I think because the chemical sensitivity came up, in addition to other things, they sent me to an occupational therapist to be evaluated for sensory processing disorder, which I do have and was verified through that. Again, you know, I haven't been tested. I'm interested to find out if I'm on the spectrum, but I don't know. I can't afford \$4,000 just to have that, but they just kind of chalked it up as part of this sensitivity issue in general—I don't know even how anybody is. I still have yet to see an immunologist which I would think would be kind of a first line if you're continuing to say, “I have these chemical sensitivities and they're getting worse and more broad.” As it stands right now, say last night, about an hour or two after I got off the phone with you, I definitely needed to take a break and recalibrate. I had to make dish detergent because that's the only safe dish detergent we can make; so we make our own just because it's at that level of sensitivity with these chemicals that it's—yeah. I've just noticed my whole body, my whole mind, my whole everything change over the years that I've been able to kind of control for a mostly chemical-free home. It's really different. I mean, as I was growing up with it, I was just constantly activated because of these perfumes that were starting to come out in the '80s, just constantly itchy, so much so that my nickname growing up was “Schpilkes” which is so full of emotion: you can't deal with all these emotions. This is interesting to think about it, as we're talking—I hadn't really thought about the chemical sensitivity thread as much until this conversation either so—

YIU: I see. I wanted to go back. You said that they referred you to an occupational therapist, why did they refer you to an occupational therapist for chemical sensitivity?

HUMPHREY: Because they were chalking it up to Sensory Processing Disorder. Again, this is, “It's all in their head” thing. Kaiser Permanente had me checked out for migraines. I went, took all these ridiculous medicines. They sent me to a neurologist only for pain management and then once they realized that I wasn't making it all up, they referred me, then, to an actual neurology workup and then simultaneously sent me to the sensory—the person who could identify— could diagnose— Sensory Processing Disorder, because chemical sensitivity is part of the spectrum disorders. I think it was just kind of chalking it up to this behavioral aspect or component of my experience.

YIU: I see. You mentioned that you make your own dish detergent and that now you have learned to, you know, control how to live a chemical free environment within your home. Can you tell me a little bit about your rituals?

[00:16:24]

HUMPHREY: Sure. Well, I started getting really interested in natural products since I was really young just because of trying to find solutions for my own stuff and with my family. Then when I was in my early 20s, I started working for an acupuncturist and she would make all these little thrown together—she was basically a kitchen witch. She would throw together these little remedies or whatnot or cleansers for her house and so, I got inspired by that and was just interested in how to make things; so it's been something I've been curious about. I started playing with making my own body products or whatever—kind of forgot about it because life happens, you get really busy. (As a result), I started having a lot more rashes again and sort of getting—I can't think of it, this is that memory thing I was talking about.

All of a sudden, my eczema got so bad when I was nineteen or twenty and I realized it was because of the cleaning products making contact with my skin and then stress and sweat and all that. I started doing salt and sugar scrubs, to kind of help get some of the impurities off, or whatever, to draw it out. Then, I guess, around 2010 or 2011, (is) when I absolutely became anaphylactic-ally allergic to gluten and started to find out how many things had gluten in it, especially “natural” products: the vegetable glycerin and the vegetable-based things. A lot of them had gluten byproducts that my skin was reacting to and so I took all this gluten out but was still having all these hives and reactions. My tummy would go and then the headaches, and then I get those bumps in the back of my arm and all that stuff is going. That's when I did total inventory of my home. I had already been interested in playing with some of it for a long time, looked up some resources, put everything through, (but) at the time I was heading back to graduate school, and it was not long after the recession so I couldn't really afford to buy all of these really natural products. It was ridiculous how expensive they were so, I just started making them and I figured out the ones that were easier to make—I was making my own laundry soap for a while which requires grating bar soap and I kind of took that off the list because I can't do all of it.

Now at this point, I've been doing that for ten years now. I have the foundation of all of my body products, except for certain soaps. All of my household cleaning products, except for laundry detergent, are things that I make, and I've been just making the recipes happen. I can just tell, even as sick as I've been, the one aspect of the burden has not been my body's reaction to chemicals. Because that is the smells, like the headaches, the nausea, the itching, (the symptoms) that I get from being in a home—it's like Glade plugins, everybody uses mainstream lotions and soaps and stuff—I can feel that almost immediately when I walk into somebody's house like that. That's just hasn't—It's just not there.

YIU: Yeah, I mean, it sounds like you're definitely very thrifty and masterful in terms of putting together an environment that is livable.

[00:20:07]

HUMPHREY: It's a lot of effort.

YIU: Yeah, for sure. You mentioned that, you know, they chalked up some of your symptoms as anxiety. And have you ever (sought) mental health professionals? And how do you deal with the stressful condition of, you know, finding out your diagnosis, changing your job various times, establishing your own practice as we were talking about?

HUMPHREY: Yeah, I stay very connected to—I mean, it's, I call it a web. It's my web of care, and I stay really, really connected to those resources. I always have a therapist; right now, I don't. I'm excited (because) I just got insurance, so I can try to find somebody new locally, but I started working with somatic therapists about—Oh gosh, I can't even remember the, I'm not remembering but it's been several years, and it inspired me to take my training towards somatic therapy. Part of it has been the integration of my own practices of really listening to my body, you know, having a lot of mindfulness practices. I started meditating when I was six years old so that's been an off and on daily practice—one of the only consistent practices through my whole life. I'm also a dancer, so staying in that place of really staying with my body because I do get depressed. I do have mental health issues. And it's very understandable. I have a really high ACEs (Adverse Childhood Experiences) score—I was actually jokingly going to (find) a club called the High ACE or ACEs High Club for people that have a high ACEs score who are figuring it. Because of that, I've been in contact with mental health professionals off and on through my life, and I maintain a really good consistent relationship with practitioners who I know are, you know, understanding my intersections. I have a really strong consult group of mental health clinicians that I stay in contact with—I maintain mentor relationships, and a really, really active spiritual life. It's not like I do it perfectly all the time, but I have to keep all of that in place.

I mean, in the same way that I've learned how to advocate in health environments. I've been really having to learn how to advocate in relationships as well. Because there is a lot of mental health stuff that comes with this, you know. And it's really confusing, growing up feeling like you're the only person who is sensitive to everything and just being told you're too much or “Oh my god, you're making it up” or you're being dramatic. You have to have some reality testing and maintaining those relationships helps do that.

YIU: You used a phrase that's really beautiful called “web of care.” And you mentioned that your web of care includes your spiritual practice, but also your somatic therapist that now you're going to build another connection with. How do you feel after finding a community of folks who were able to provide you with care? Do you also have relationships you developed with an online community?

[00:23:34]

HUMPHREY: Oh, yeah, with an online? Absolutely—actually one of my dearest kind of comrades through this whole experience is a person I met through an online class and that is sort of a—I just kind of laugh sometimes because we're in the middle of COVID-19 and so I'm online a little bit more than normal, and I'm just very aware of what some of my lifestyle choices sound like to my more conservative families. I'm kind of laughing at myself right now. So I was in this

online class of these radical witches who were looking at postcolonial Earth-centered spirituality, and how to really right-size our practice and our teachings, as people who have to wake up to the colonialism and racism that's inherent in American paganism. That's one of the ways that I maintain my sanity through all of this. And so I'm in this class and I met a person through this class on Zoom who was living in Vermont and just really connected (to). And so we just started talking and chatting throughout all of that class and then maintained a friendship online. I didn't meet her in person for a year and a half, supported each other through Lyme. Every discovery that we found or like piece of writing that we thought was credible or checking it against, you know, other resources, we'd be sharing and really supporting each other through. And because we had met through this shared kind of cross intersection of political and spiritual practice, we were able to support each other that way as well. And I think one of the things that really stitched it together for us as well was that they're Palestinian, and I'm a non-Zionist Jew. That also kind of helped really hold that resource and hold the sanity-making of it, you know?

Yeah, definitely all online and using tools—It was mostly because of my vision... I can't do a lot of looking at screens. And when I am looking at screens, I have to have a lot of filters, so writing on screens, that is a little challenging. Anything I can talk into or do videos with—honestly those are where those relationships, either mine or through friends or my partner who's a little bit more screen-able, they're really active in our online Disability Justice community; that's where we get the resources to start with. This is where we're learning, the same thing as when I was growing up. This is where we're learning where to go look and find out. I'm always about measuring it against research and finding out who (are) the resources; but I'm finding all my best leads and understanding and depth of knowledge from these online Disability Justice communities.

YIU: So this person that you met in this radical witch workshop, do they also have Lyme or do you have a Lyme support group that you both have?

[00:26:45]

HUMPHREY: We have supported each other through it. Some of the mainstream Lyme support groups tend to go a little bit more—I don't know, it's the inventory of symptoms. People are just really stuck in looking at their symptoms. Or the conspiracy wormhole. And I haven't found either of them very supportive of my own growth and healing process. And so we kind of have become each other's Lyme support group. My partner, also who I met two years ago, in the midst of all this, turns out they also have Lyme. They discovered that through hearing about the kind of symptoms I was having. Then I met another person whose partner had Lyme, and we became good friends. It's what I do in any support system. We are each other's support group around Lyme, and we share with each other. My friend who lives out in Vermont—yeah, that's kind of been how we've gotten through. A lot of this is really (a) holding space of “This is what it's been like, this is what it feels like, this is the reality and gravity and art,” and “Oh, are you noticing this,” and “Are you noticing that,” and “What is that teaching us about, you know, X, Y and Z?”

And then my former roommate's partner, it turns out, is a documentary filmmaker and he's been making a documentary about Lyme. It's really powerful. It's really beautiful. I'm just blown away by how gorgeous this thing is. And he's got this temperament: like he's kind of my token cis guy

right now that I really adore. He's very straight, very white, very much a dude. And he's just a wealth of knowledge, though, and courage, and he doesn't kind of take this tactic—he's aware of all the conspiracy theories; he's aware of what holds water and what doesn't but you know, we can all validate how fucking hard this disease is to live with.

Yeah, it's just been—I'm having these relationships, kind of one-on-one. When we need to be like, “Hey, I need a little space to process about this, do you have to have some time?”—we make that time.

YIU: That's beautiful. And you mentioned a little bit about an online Disability Justice community: is that part of your advocacy work too alongside with your partner?

[00:29:21]

HUMPHREY: Yeah, I mean they're a lot more involved just because they have more capacity. But yeah, my partner and I actually also have a practice together called Luna Soma that kind of came up around us trying to figure out how to do any and all of our skills that we love in a way that would honor our disability and burgeoning disability because we've been sick for such a long time; you just don't know when you're going to or if you're going to come back to whatever, you know, baseline. We started doing Luna Soma and, currently, we're along with a couple other practitioners posting little helpful videos to help people stay grounded or kind of come back into awareness while they're so activated due to Coronavirus through this web of people sharing from your Instagram post or whatever. We're kind of supporting each other.

Luna Soma is something that Golden, my partner, and I do together that, you know, kind of started from the conversation of how we're going to make a living. They were training as a nurse midwife and got really sick and had to figure out what else are they going to do? They're a craniosacral therapist and an herbalist, practicing herbalist, and I'm doing somatic work, but I also do a form of touch work and energy work that's outside of psychotherapy. And then I do consultations, and I'm also training as an herbalist; I've been doing herbalism for years. So we're finding ways of posting things and sharing things and amplifying other people's work. Before I talked to you today, I did a video that I just realized I have to re-edit, a ten minute video about an orienting practice that can help you kind of stay heart-focused when your nervous system is trying to run amok. So yeah, definitely—

YIU: Where are these resources available? That sounds like such amazing materials on offering health advice that is more alternative and self-centered.

HUMPHREY: It's Instagram and some Facebook. I mean Facebook is like eh, you know? But Instagram and I'm sure there's other platforms. I know a lot of people are using TikTok and all this stuff. I'm not as familiar with them, but I've come across most of the people that I'm in contact with through Instagram. And through a lot of the podcasts—you'll hear a lot of shout-outs on podcasts. And so, I think if anybody was just going to start somewhere, (it) would be “How to Survive the End of the World”. It's a really great podcast to start with. “The Healing Justice Podcast”—really putting a lot of resources out there. But yeah, I mean, it's—I would even just go online and put Disability Justice. And there's—I'm right now just not remembering

everybody's names—but there's just a wealth of incredible resources out there. Everybody's doing it on Instagram, some Facebook.

YIU: Amazing. It seems like the online community is a way of navigating this illness and being able to do social things while managing your illness, is that right? Or, how do you manage socializing in the day to day?

[00:32:40]

HUMPHREY: I mean, yeah, that's just it. So it is to some degree, but for me, it's ultimately just part of it, having phone calls and conversations and hearing each other's voices has been, for me, really important, using Marco Polo where we can have videos. There's three or four people that I stay in really close contact with, but, otherwise, it has been a challenge. I mean, we have to be really intentional about when and where and how we spend our time and who with, just because of sensitivity issues and illness. For some people, it's really hard to be around us when we're sick. And quite frankly, it's uncomfortable for me to watch someone else be totally uncertain what to do with themselves because I'm trembling you know? It's just—not a lot of people who are comfortable being out with their disabled friend anyway. I just had to say that complexifies it.

But little dinner parties—we'll have people over for dinner; we do some shared ritual at different pagan holidays or whatever. People will come over. We have a dear friend that we do Shabbat with who will, you know—when we were living in the same community, would come over and share a meal or maybe we meet at a park. But we really live a very daytime life; if I don't go out and meet someone for tea before two or three in the afternoon, there's no telling what could happen. My energy tanks out mid-afternoon, and if I have to do something in the evening, I don't do anything during the day. It's kind of like scheduling for a little kid; I just have to say “Okay, well, they're definitely going to need a nap after this.” We'll meet for three hours for pancakes, and I'll go home and take a nap and that's kind of it for the day. But you know, we have some really good friends, but it's few and far between: people who actually still stick around when you can't make it to the party, or you can't make it to the loud event or you can't make it to X, Y and Z or you've had to cancel last minute, the last three times or whatever. It's a sweet little collection of really beautiful friends, and I'm just very fortunate for that.

YIU: Yeah, it sounds like it's difficult to manage scheduling. Does your illness or sensitivity affect your relationship with your family?

HUMPHREY: Yeah, deep, deeply. It's been difficult. And now that I've come back to Missouri, and I'm living in St. Louis—you know, my family lives in this huge building together, my parents live in the main house downstairs and we're in the third floor apartment. It's meant to be a temporary situation, but who knows how long now that we're all—what is it that we're at—peace in shelter right now?

There's a lot of narratives that come up around a person when you have multiple sensitivities and when you're feeling things, you know, at a ten when everybody else is feeling it at one. It's been a lot of figuring out when or where to make amends and when and where to hold accountable the places where there's been some not fair summations and opinions of me and of my sensitivities.

There was always this, “Oh, you're being dramatic,” or “Oh, that can't possibly be real,” or “Oh, come on now,” but then it's like, “Well, yeah, but you see the rash on my arm right now.” It's not not real. But then the pendulum swings to the other side like, “Oh, I'm so sorry. You've struggled so much, you've suffered so much.”

I've become profoundly creative and resilient and, so, it's just been interesting. So we'll see. I mean, unfortunately, I just feel as the person who shows the symptoms more than others, I definitely have had that identified patient experience in the family in the past. Coming back, my family has always really prized medical opinion—here I'm coming with this suitcase of medical opinions that verify my experience, and it's watching the shock on some folk's face and then the validation from others of, “Wow, we have always wondered kind of what the fuck has been going on with you,” you know? Because there's this combination of figuring out, yeah, I'm dyslexic and I have sensory processing disorder and Irlen Syndrome and photophobia and migraines with aura, and I potentially have some other neurological stuff because of the kind of genetic impact of Agent Orange. And then yes, now I have Lyme, and that has been complicated by these things so—

[00:37:33]

YIU: You mentioned in our last interview—I mean, it was just yesterday—that you did some self-research, and it was from your father too, that you understood the genetic relationship with exposure to Agent Orange. Can you talk more about that?

HUMPHREY: Sure. Well, I think I mentioned that we all used to get these weird rashes at the same time. And nobody else got them. That was one of the things where there's clearly a link because that's just strange. Nobody else is getting them, and it is a very specific form of rash: it's called chloracne; it's very specific. So that, in and of itself, in your own body is like, “Well, that's interesting that that would happen.” Then, in the '80s, they started coming out with this research, and my father and his activist comrades were circulating this research and talking about it and speaking at rallies about it. You start to hear, “Oh, my gosh, you know, we're coming so close, they're validating these midline deformities,” which, at the time, I didn't know what that meant, but it's cerebral palsy and things like that. And they're like, “Wow, that's a genetic thing,” which I again, didn't quite understand any of that. Then that research kind of disappeared from my consciousness because life is what it is. I got more interested in becoming a psychotherapist and artist and all that stuff.

It came back around when I was just trying to figure out the sensitivities and the sensory piece and trying to piece apart why my experience was so uncomfortable. And I again came across some research about two years ago that had picked up where that earlier research had left off, and thought, “Yeah, we sure are seeing all of these people showing up that our kids of vets, you know, next generation who are now into adulthood in Vietnam, as well as the United States, with these neurological and sensory disorders, learning disorders, higher autism occurrence and ADHD and all of these (disorders).” What it's looking like, and what the curiosity is, is that there's this genetic switch and my understanding, just as clinician—you know, I'm a counselor working towards my professional license—is that there's this thing called the Stress Diathesis

Model, where in our genes is this potential, and that all you need is something to flip the switch and then that creates the illness. And we see that intergenerationally; we see that, you know, from chemical traumas or whatever. And so given the way that my early childhood and having the developmental trauma with my ears, and the painful infections, in addition to all the emotional trauma, that's all it takes. All of a sudden, this thing was potentiated in my dad's DNA that hadn't been in his dad's DNA; so the only difference is that my father had been exposed to this chemical that they were now finding was causing the things that were curious in mine and my brother's experience. So that's kind of for me how the whole genetic link came together... just combining and remembering what I learned when I was a kid, fact checking, but then also everything I've learned as a clinician about how these genetic predispositions come into disease or don't come into disease.

YIU: So you mentioned that you are an artist, and you're a dancer and in your previous work, you have done some psychotherapy and as a crisis clinician as well—what do you find yourself doing now as a form of hobby since you do have chemical sensitivity?

[00:41:44]

HUMPHREY: Yeah, well, I mean, making those products becomes part of it, because if I don't enjoy it, I'm not—and so, I do make a lot of (those), I do a lot of kitchen alchemy. I cook and I make body products and I make teas. You know, especially since I'm starting to get better, I'm not in bed; I've been in bed quite a lot the last couple years. My work is kind of—I don't know, I need to make any better boundaries around it. I started hosting this meditation and part of what I started to do with the meditation—there's this heart focus practice that I learned from the HeartMath Institute, and it's meant as a way to help people connect through intention and practice—is that I'm really interested in gardening, and I've been doing it my whole life. My mom's a gardener and my grandmother's a gardener; it's a long generation of gardeners. And so I've been really interested in biodynamic gardening for years. My career up to the point when I went back to school—the recession hit me really hard—my career was in food. I'd been a chef for eight years up to that point and worked one-on-one with market gardeners and really found that anytime I worked with biodynamic stuff, it was incredible. So, I want to go back to that curiosity. Now, all of a sudden, that interest in biodynamic gardening and farming has informed now how I'm doing my meditation practice and is now informing how I'm envisioning my practice. I do consult; I do consultations. I have a few clients that—I think I have four clients right now that come and go. I do consultations as far as integrating somatic awareness and mindfulness and growth into their lives, or people who are working with clients that they need a trauma-informed perspective. The consultation feels really nice but I feel like all of my curiosity goes towards what ultimately ends up in my work.

My hobbies I would say right now: I'm doing a lot of sketching, a lot more collaging, and I just was finally able to get my hands on a Freewrite, which I don't know if you've ever heard of—

YIU: Free writing?

[00:44:06]

HUMPHREY: No, it's a machine. So I can't—I have the screen difficulties but I also have pretty bad arthritis from Lyme, so writing by hand has gotten pretty (difficult). I can only do so much every day. Writing has become a challenge. And I finally was able to get—it's \$500 for this thing, but there's an LCD screen so it's that new kind of paper white, ink technology and there's a little typer so I can actually write again, so I'll be starting that. I just got it this week so thank god, right when all this started happening. I guess I got it late last week, actually —

YIU: That's perfect timing actually. So—

HUMPHREY: —And my hope is—

YIU: Your hope is?

HUMPHREY: Oh, that'll be—I'm trying to go back to work part time, obviously, once all of this is over, so we'll see.

YIU: Definitely. But you said that now you have, in and out, four patients. How do you see these clients? Is it online or over the phone?

HUMPHREY: Yeah, well, they're not patients. So the consulting clients are just clients—I'm not taking anything that would be construed as a patient right now. That, to me, is—that's what I probably will do, five or ten clients maximum, when I go back to work as a counselor, and that would be kind of the more, quote unquote, patient population. But the folks that I'm seeing right now, a couple of them, up until quarantine—we have a studio at our house where we both do bodywork on each other and where the consulting clients will come; otherwise, they do it online through Zoom.

And it's actually pretty remarkable the amount of somatic work you can actually do because I use somatic experiencing also in my consulting clients. A lot of it, in the consulting clients, is trying to help people who are helpers and practitioners really ground their experience in their own body, ground their kind of change process in their own body. These are people who are—they're not necessarily needing a therapist, or they're working with a therapist, but they're trying to figure out how to make the change show up in their life. I'm just doing those consultations, or they're trying to understand how trauma or patterns are holding in their client's bodies. And so I'll talk to them about how they can conceive of that, how trauma acts in the body. As a consultant, it's, yeah—I'll do that. Right now, I'm doing it all online, but it works really well.

YIU: Yeah, I think it's really, I don't know, revolutionary to think about online somatic therapy. I've never heard of that before so it is interesting.

[00:47:04]

HUMPHREY: It's really interesting because I entered into somatic work from the doorway of talk therapy so I'm already having to figure out how do we get into the body without, you know, touch, without anything. I now do a form of touch work but it took me three years of intensive training and then another—I'm in my second year of some continuing ed (education) about experiential, somatic psychotherapy work. But I think because we're doing so much of that “I thou” work already, of just tracking and honoring and listening—I have a really good ability to

track. I'm also— what doesn't matter if people believe it or not, but I'm called an empath, and I can literally feel in my body aspects of what's going on with somebody else, and they just kind of trust that. I can't say that I know it exactly but I'm like, “Oh, there's something I'm so curious about. I know something happening in my stomach, what's happening in yours” and nine times out of ten is “Oh, my god, I hadn't even noticed XYZ is happening.” Whether that's mirror neurons or not, somehow it works. And I think because I entered into it already not in the purview of touching a body, because it was not my scope, it is now—because I have certification and all that and you know, but—

YIU: Yeah, so we've been talking a little bit about Lyme. But you've also mentioned that you had toxic mold exposure, did that come to be because of work or where was this mold exposure?

[00:48:50]

HUMPHREY: Well, I went out to the Pacific Northwest to take care of my dad and his end of life, in Oregon. I was still having some Lyme stuff but it had gone into kind of a remission, which, you know, I later found out was kind of common. But then I moved—I was starting to have some immune system stuff. I didn't know if it was just acclimating to a new environment. But then I moved to the city and stayed in an apartment that—I'll occasionally do some fermenting stuff, and I noticed that my ferments were getting moldy really fast, and so I just kind of scrapped it because I was only going to stay there temporarily. But then I started noticing every time I took a shower, I was getting hives, and I was having weird visual stuff that was stronger than it normally would be and lasting longer than it normally would because I have a lot of visual anomalies with migraine and other things. Then, after that temporary housing, I moved into another place and then all of a sudden. I was having weird nightmares and my moods were hard to get a handle on. I was also having a really hard time at work at that point. I was really bumping heads with my supervisor who was just not wanting to accommodate me. And so at the time, I wasn't sure whether my sensitivity (was) higher because I'm stressed or—but I started getting migraines every other day and then rashes everywhere. All of a sudden, getting allergic to food that I hadn't been allergic to.

Things were just not okay: I started hallucinating in ways I'd never hallucinated before. But this was also while they were trying me out on all of these psychotropic drugs for the migraines because I was in the care of Kaiser Permanente at that time, so I couldn't really parse it out. And eventually, enough people—my partner came and moved in with me and then they started having the same symptoms I was having, despite already having different ones. Enough people said, “It seems like you get worse when you go home,” that I then started to know what questions to ask. And, you know, found out—I mean, I don't know if I ever found out exactly what kind of mold it was—it was a yellowy colored one. It was a long process but once we finally moved out of that house, unfortunately, the housing we moved into, it turns out they had mold, but they had an even worse strain. So, it ended up being a year and a half of living in homes with toxic mold before we finally, you know—we ended up in Montana for six months for my partner's job, and then their job got mold. We came now back to St. Louis, and thank goodness before we moved back here, my family had already checked for mold and remediated the mold that they did find. It was a year and a half in our home and then just coming to find out it's basically a huge

problem in the Portland, Oregon market and was not very likely we are going to be able to escape it there.

YIU: So it's just a permanent condition in Portland?

HUMPHREY: Yeah, unfortunately. I mean because it's just people aren't taking the steps to remediate it properly. The building codes have changed such that they're using this certain type of insulation that holds all the moisture in and then not putting enough circulatory fans in the houses because they're trying—they're not, they're not updating and upgrading the HVAC system. And then people have this—It's really sweet but people will leave stuff out in the street and take it home with them, so they're just passing around all this moldy stuff, going from house to house to house to house.

YIU: And this would be five years ago?

HUMPHREY: We just found out about the mold—we actually lost our house, I would say, last March, so it's been about a year ago. I've been in treatment for mold for about a year.

YIU: Where have you been receiving treatment for mold?

HUMPHREY: When we were in Montana, we were seeing a naturopath who specialized—you know, in Portland, we first started getting treated there with our naturopath who specialized in chronic Lyme and infectious diseases, which mold falls underneath. And she was working in Portland, so a lot of people were dealing with it. Then when we got to Missoula; we were working with that naturopath. We were actually in the process of getting set up with immunology there when my partner lost their job. We'll start working and again—it's just been unfortunate timing because we got a referral to an infectious disease person, but then three days later, the government started taking action towards COVID-19 so we're kind of dropped on the priority list until this passes, so—

[00:53:54]

YIU: That's terrible. So earlier, you mentioned a little bit about you asking for accommodation at work: can you talk a little bit more about the process of asking for accommodation at work? How people have responded? You mentioned that your supervisor was not receptive?

HUMPHREY: Yes. Well, this was the first time I—well, that's not true. I mean, I asked for accommodations at my first job where it was clear that the lights and loud stimulus was really triggering me and interrupting my ability to work. So there was this office off the side of the main room; the daytime case managers were there during the day, and I worked evenings, so they set up a little corner for me where it was low light. I was separate but still connected to the rest of the room. That was very helpful; ultimately, it didn't work.

Then at the next place in asking for—because prior to that, I was working as a chef or freelancer or I was in school or I was doing administration in these really low stimulus, holistic healing environments anyway, so I wasn't needing accommodations. It was already well tailored to my needs.

It was when I got into agency work that—so when I was talking to that administrator, it was, you know—I have these learning disabilities and they kept calling me out on certain things. So again, “I just want to clarify, you know, I just switched a word, but that’s also really common in dyslexia; it doesn’t mean that I’m being, that I’m not being mindful, you know?” She was always trying to say, “Well, you’re not being mindful, you’re not doing this,” and (I’m) like, “Okay, so again, here’s this thing, and if we could step away from that, thank you for pointing out my error. Appreciate that. And also, if we could find a way to use this program that I am more comfortable with, then we might have a better time communicating.” She was insisting, “No, we have to do it my way or whatever.” And then just in saying, “What I’m noticing is these migraines are coming on and I’m having a hard time focusing on my notes afterwards because my nervous system is activated,” because there was only five minutes or seven minutes, but really only five minutes between clients, and then we were required to see five, back to back. You know, part of migraine maintenance is keeping your blood sugar at a constant so, you know, I’d have to walk down the stairs and go into the kitchen and get a snack and then run back up and it just was really not working for me.

I said, “Is there any way we can like, break up my schedule?” She said, “No, we’re too small. We can’t do it. It’s too confusing.” So I said, “Okay, well can I ask for these different light bulbs in here?” She goes, “No, we don’t use those light bulbs. We use these energy efficient ones, please stop moving the furniture.”

It just was—and the fact that she was a really small agency and a really difficult personality, and I felt pretty confident that I could start my own practice—I just kind of ended the conversation and chose to, you know, take things in my own hands.

[00:57:05]

YIU: Can you tell me a little bit more about what some of the changes you made for yourself (were) when you have started establishing your own practice to make it a more workable condition?

[00:57:21]

HUMPHREY: Well, there’s no overhead lighting. I don’t use any fluorescent or LEDs. I use only warm incandescence at lamp light and I do enough of it that it can be bright if needs be. I look for a space to work with people with a lot of natural lighting. I always make sure there’s a window to keep air, fresh air moving through it. I ask that people not wear, and especially because my population that I work with, to not wear chemicals, or perfumes. If they do, I just have a conversation with them about it, you know, whatever. I work with it, but I do a lot of work in the space to make sure that air is really clean, and I vacuum and dust and all that stuff I get. I keep a pretty tidy place, not anal about it, but these things just kind of builds up and add to sensitivity.

I keep very clear hours about when I use the Internet and when I’m doing emails and text messages. And I’ve noticed that that has actually had a really great, unexpected secondary effect and that my clients don’t start texting me every time. They really, you know, take that as an

invitation to use their tools and to—then we check in or they ask permission to check in. It's actually been really cool because I'm noticing how my clients engage with media with me differently from what I noticed my colleagues saying is their experience because they kind of have these open door policies.

I limit my use of screens. I've recently decided to go—I was doing all paper during the year and a half that I was dealing with mold. I was doing all paper documentation. I have special paper, special colored paper that I use for everything. It's an off—almost like a grayish color, a beige grayish color for all my paperwork. And now, right now, I'm working with my supervisor to streamline in EHR, electronic health records, so that I can get it done really quick. I've figured out how to do—If I am doing something online, I figured out how to do my notes in under three to five minutes per client and if I need to do more, then I have a format of just writing it out by hand and scanning it in.

Just really making all of my tools more user friendly to me and making my space not just more friendly to me, but to anybody's experience. I keep really good sensory tools. I have a balance board in my office. I have weighted blankets. I have textural things for people to hold and play with, which I do as well, and I wash them regularly. So, I have props in the room that help keep you comfortable and things to lessen stimulus, and I used to work with essential oils a little more than I do now, but I'm not doing that as much anymore. But using all of the kind of sensory tools that we know from Sensory Processing Disorder and occupational therapy that help soothe—I just make sure it's readily available in my workspace.

YIU: Wow, so these sound like it's literally building a geography of comfort as well within your own space.

HUMPHREY: Absolutely.

YIU: Yeah. I have never heard of textured tools, and I'm going to look into them myself. So it seems like you're managing, finding a work schedule that works for you even though asking for accommodation has been difficult within your past work. Have you had any times where you advocated for space that did go well other than changing the light bulbs or do you find that it's been pretty pandemic and systemic that folks have just disregarded your concerns?

HUMPHREY: Well, I would say yes to (both). Yes, I've had good experiences asking for accommodations. And I think it's a pandemic in the system. I was really lucky that the five years I was in graduate school, I worked for a holistic healing clinic and they were very validating. Their ethos was meet a person where they are—I mean, that just tends to be kind of how traditional Chinese medicine works anyway and that was the ethos that guided that office, and the two offices that they ran. You know, it's not about what our opinions say, it's about what the body's telling us. So if I was saying to them, you know what, “This lighting is really not working for me,” they're like, “Great, what kind do you need? Let's put it in here,” you know? Here's the specialty—they got me a nice little, I can't remember what they're called where you put your wrist on it when you type? There's a jelly kind that I cannot deal with. But one of the admin people loved it so they got me my own and a special place to put it (but), you know, they couldn't figure out my freakin' pronouns to save their lives.

So it's always something—you just get—but yeah, it's happened. And in the greater kind of architecture of our society, it's smaller and smaller spaces, and it's really becoming more and more incumbent upon us to make our own spaces. You know, my partner and I accommodate our disability really well. It's just hard because we're both disabled so we're having to build everything from scratch and get used to the timeline of what that looks like when you're disabled.

YIU: So you have mentioned your partner and you being involved—well, them more primarily—within a disability online, community activist group. Do you consider yourself as a community organizer as well?

[01:03:26]

HUMPHREY: I think I used to more. I forget that—you know, again, culturally, there's this great archetype of the yenta. And there's something really beautiful about being a yenta, really good at knowing people's stories and how to connect them through their stories. We kind of make fun of people calling them a yenta. It's not meant positively but I think I've always kind of considered myself more like that. I'm really good at connecting people.

I think in the past, I really considered myself more of an organizer. It's just my nature. I've been doing it since I was a kid, I used to wrangle all the kids together to put on a play, you know, to the Mary Poppins record or whatever. It's just that need to help people connect. I wouldn't say, right now, I'm such a community organizer. I'm more just putting some stuff out there to support people. But yeah, because there's a lot of responsibility that comes without that right now, I'm just—I haven't been well enough to be a point person for organizing.

YIU: For sure, and I think despite of when you did it, you were certainly a community organizer at some point. Do you remember a significant moment or event that you have advocated for certain things? I remember us talking about when you were young and you talked to folks about Agent Orange.

[01:04:53]

HUMPHREY: Yeah. Well, we were doing—in art school in college, we were doing zines for a long time, bringing a way to labor issues, so I remember bringing together a small clutch of people to put together these zines and figuring out ways of slipping them into the right people's hands.

Recently, here in St. Louis, that's where I get a little bit more emotionally charged. I'm not as—I'm not in the place right now of heartfelt nostalgia; it still kind of hurts. But, you know, there was an event where—I'm not going to get into the details, events, I'll leave it at that—but there's these events of civil unrest, and there's little pods of us that, this one event that I'm thinking of, in particular of how to organize all of these people's telephones, charging stations, food, who's who in what jail cell, who's been transported to what holding facility and then having to be a point person. So I was—in those experiences definitely a place between many other organizers. “Okay, this person has this phone, this person has that phone, we're tracking these three people through this system. And this person's tracking those four people,” and it's almost like being that operator switchboard.

Then we also organized, through my program at school, a healing arts unit, so being part of the committee and writing the grant, the languaging for the grant. We eventually were granted pulling together a mobile, sand tray, kind of mobile arts, healing arts clinic, and then pulling all of that together, getting all of the nuts and bolts: “What are the bags, how many boxes, how many toys, how many people who's going to be there to do the emotional processing, who's going to be there to do the cleanup,” you know? Yeah, that was, I don't know, very different than what I'm doing right now.

YIU: For sure. Yeah, it sounds like you have multiple careers shifts within your life from being a chef to just gardening to being your own crisis clinician and everything. Are you proud of any particular moments within your activism?

HUMPHREY: I'm proud, I think, of all of them to be quite honest. But recently, maybe it's my age or something, there's some of them I wish I would have done better. You know, I wish I would have been louder, or I wish I'd stepped back a little more. I wish I could have been more active physically, but I was so sick. But overall, I'm proud of all of it.

I'm a person who has really done a lot of time making sure I'm in my conviction, and also making sure that I can accept pushback. It's fine, you know, we all are having these different experiences. But, lately—I don't know, I'm forty-five, and I've been kind of—I came back to St. Louis, and I'm showing it to my partner and having all these memories. I'm just remembering when I was fourteen years old, my mom moved us to this town called Webster Groves. And it was pretty—for me, it was kind of a trip. It was very, I don't know, suburban, and it was just kind of a trip. It was so cush to me, but at that time, I found out that McDonald's, the Styrofoam that McDonald's was using was inadvertently leading to the death of baby seals and other animals. And I was just, “This will not do. That is not okay.” I was really upset, and I took it to my mom and I was, “This is not okay, that will not do. We have a McDonald's in Webster and all of these people are killing baby seals and that is not okay.” You know, I was not a really popular kid at that time, so I decided, “I'm gonna do a protest.” Nobody wanted to do it with me. Fine. I made a big poster that said, “Stop killing baby seals. Say no to Styrofoam.” And I sat in front of the McDonald's in Old Orchard and Webster Groves by myself, anxiously chewing the straw—who knows, some hypocrisy. But I would say that one, if I really —maybe it's just where I'm at right now, I'm very nostalgic, but I'm really proud of that kid being, “That is not okay. I don't care if it makes me popular or not.” And then later in high school, I started this Earth Action Alliance Network, which I recently found out is still a club so I'm proud of that kid, so much.

YIU: Wow, that's amazing. And it really paints that genealogy of you that have just always been an activist at heart.

[01:09:42]

HUMPHREY: Yeah, I think it's some of us are the kid on the playground, they're, “No, you just hurt that kid for no reason.” Some kind of stay playing or, “Oh, God, hope it's not me,” you know? And I've, unfortunately, inserted myself into places whether I should or not.

YIU: Yes. So I am conscious that we're at an hour again, and I want to start wrapping up; are you doing okay in terms of your energy?

HUMPHREY: I'm feeling okay, but I'm also noticing that, yeah, it's been really interesting to have these conversations, but it is very activating. I really appreciate you checking in.

YIU: Yeah, so I want to turn to two last questions and one being I want to learn more about your creative outlets with coping with your illness and sensitivity.

HUMPHREY: I've always been really curious. I think I may have mentioned but I spent a lot of time at the library when I was a kid. And I just remember Oscar Wilde said this thing about, "You get to the soul through the senses—you speak to the soul through their senses, and through the senses you speak to the soul." Creatively, it's really been about engaging the senses and doing things that feel good and not just at a hedonistic level, but at the, "Let me engage my joy and meaning" or whatever. So my creative process now, I would say, has a lot to do with currently trying to frame it through what is accessible to me. You know, I got this new Freewrite, so that I can start writing because I do a brain drain every morning; because it's very important for somebody who is, on the kind of—in the milieu of processing styles that I have—to do brain drain. A lot of ADHD and dyslexic folks do really well with that. That, inadvertently, kick-starts a creative process so I write a little bit more.

I do a lot of collage; I'm figuring out ways of reconnecting with collage without using computers because I can't—I just can't. Then, right now, playing with vocal toning, because there's this way that I have had to really retrain my autonomic nervous system using breathwork. And so now, I'm doing vocal toning and compiling some stuff to start playing with a mini keyboard with my partner, you know, to start collaborating creatively. So right now, just kind of playing with what works. What's starting to land is I'm coming back to paper cutting, collaging, zine making, writing, playing with textures and colors. I make little dream pillows that are filled with herbs that are helpful for settling the nervous system. It's really become: how is the sensory stuff been giving me access to mediums—and now I'm kind of playing with that. Because really, I was working full time and sick, and I'm only just getting to a place right now where creative outlet is—there's space for it, you know? And the way I engage with it is also different now.

YIU: Wow, I am going to learn some of these rituals that you have mentioned. To end our conversation, I want to ask what some of the steps that you believe are to change our society's relationship with chemicals and smells and what we associate with these things.

[01:13:30]

HUMPHREY: I mean, the first thing that popped in my head was that we all need to start learning to center the experience of the person who's speaking. And instead of rejecting outright something we don't understand, or we've never experienced, be(ing) open to the idea that these are real experiences that people are having. Yes, it might be an inconvenience to what is your comfort of life, but at the end of the day, meeting the needs of people who are chemically sensitive is actually meeting the needs of everybody. Nobody really loses except for the people who profit from these chemicals being out in the world. And so to me, even just to all the

medical issues, it's really helping people, “Hey, you know, let's step back and just hear and listen to this person's experience.”

How do we start creating spaces for people that include everybody, or being comfortable with the fact that it's not going to include everybody, and we don't have to reject outright? I mean, I don't know. Because for me, it's how do we kind of change people's hearts and minds, you know? How do we start validating that these are real sensitivities through policy, or whatever, because I feel like it's such a big ship to steer that a lot of people get lost if we try to take on the whole systemic thing. I know that they're doing all this work to train practitioners; they're kind of going back and training practitioners on things like motivational interviewing and bedside manner. I just think more of that empathy and compassion building (is needed) because I don't know how we change the system right now. I don't know how we change this, right now. Too many people are profiting from it being as it is. I just really don't know. But I think things like what's happening right now is actually helping people's creative imagination a little, to be a little bit more understanding that there's impacted things we don't see and don't ourselves understand. So that's my—I guess, I don't know if that's really answering your question but—

YIU: Yeah, it is. Thank you so much, Ray, for your time and your energy and just the narrative that you've told so beautifully.

HUMPHREY: Yeah, thanks. I'm a storyteller so thanks for giving me the opportunity. And I just—again, I'll be so curious to continue to learn whatever it is that you're able to do with this work and what it becomes. I think it's really valuable.

YIU: We'll definitely keep you updated. Is there anything that I haven't asked you yet that you'd like to tell us?

[01:16:02]

HUMPHREY: No, but I will say the thing that I just continue to be curious about with the chemical sensitivity piece and the people who are having it is where is our intersection of people who do have things like high ACEs and people who are neuro-atypical and who are already marginalized a bit. It's just something I would really hope that people are going to stay curious about because we're not all quote unquote “normal” people.

YIU: Definitely, yes. We'll definitely keep you updated. If we find anything in relation to that. I haven't actually heard much about that yet. But again, I haven't been the sole person that has been to doing all of the interviews.

[01:16:49]

HUMPHREY: Yeah, I feel it's just something I just always want to put in a conversation, because there are a lot of people who, you know, these chemical sensitivities pieces—there's a lot of us who are just predisposed to be a lot more impacted so—

YIU: Most definitely. And thank you again for your time.

(End of March 25, 2020 interview)