

## Oral History with Sarah Jay

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Interview with Sarah Jay  
SESSION 1 (4/3/2020)

[00:00:07]

YIU: This is Nic Yiu with the Center for the Study of Women at UCLA on April 3 with Sarah Jay. Are you in Toronto right now, Sarah?

JAY: I am.

YIU: Great. So, let's start by thinking about how your genealogy has paved your place in Toronto, and—Oh, you have two dogs. Wow, abundant.

JAY: One just got a DIY home haircut.

YIU: I see. When and where were you born? Can we start with that?

JAY: Yeah, for sure. March 3, 1981 in Montreal, Canada.

YIU: Can you tell me a little bit about your parents or your family background? Where did you live? What was the community like?

JAY: Yeah. I lived in Quebec for about four years before moving to Ontario to a small town called Kemptville, which was an agriculture town. My dad works in agriculture and is an animal geneticist. My mom was a teacher and an artist and a homemaker and a crafter. The home that I was born into was a big, old home that I don't have tons of sensory memories of, but the home that I grew up in, for the most part, was a brand new home that my parents built. I associate that with the smell of paint and the smell of wood and the smell of carpet. Even though I wouldn't identify as chemically sensitive at that time, I was always the kid who would be able to point out or pick out somebody's perfume in a crowd and associate like, "That's Uncle Paul's cologne" or "That's Terry's perfume" and match people that way.

YIU: Right.

JAY: It's part of how I am really aware of and experience the world. So yeah, I grew up in a cow town outside of Ottawa.

[00:02:29]

YIU: I see. Yes, I lived in Toronto for a few years, so it's really amazing to know that you're in Toronto and that we're speaking in this format. So it sounds like your scent experience has piqued since your youth and that you would not identify it at the time as chemical sensitivity.

JAY: No.

YIU: Okay.

JAY: This got a little complicated for me. As a teenager, from the age of fifteen onwards, I didn't live with my parents anymore. I lived in a different place every year. And one of those years, I lived in the Anglican Rectory of the Anglican Church in this small town, which was a huge ancient home where I suffered mold exposure horribly. I've never been so sick as that year. I remember reaching into my throat and my mouth to like manually scratch my throat. I was just a mess that year. I know that that's one of the variables for me. I would have been in grade twelve and shortly after that, things got markedly worse for my health.

YIU: Yes. So for those who are listening who might not be Canadians, can you tell me how old you were at grade twelve? And what were some of the signs of sensitivity that you were exhibiting while you were living in that ancient home?

JAY: Yes, my histamine response was just through the roof, like all of my environmental allergies, seasonal allergies. Eating a healthy diet has always been important to me. I was an athlete. The other variable for me is that I have suffered an extreme chlorine overexposure. I'm often swimming twice a day, working at a community pool in the summers where the lifeguarding and instructing staff also did the pool maintenance with very little protective equipment. So that's another major exposure risk that I suffered over fifteen years. To answer your question specifically in grade twelve, I would have been seventeen or eighteen. Sorry, what was the other part of your question?

YIU: Yes, actually, you –

JAY: I answered it? Did I lose you, Nic?

YIU: Hello?

JAY: Oh, I lost you. You're back.

YIU: Okay, I was just typing to you. I said, "The conversation is lagging a bit. Could you try turning off the video?" Thank you. It's this new working-at-home thing and I guess my Wi-Fi is not as excellent as I thought. I'm sorry about that.

JAY: No worries.

[00:06:15]

YIU: Yes, thank you so much. That's really stable now. So you were in grade twelve and I asked you how old you were and what were some of the exhibited signs?

JAY: Yes. I was seventeen or eighteen, and at the time, I just noticed a really severe peak in my histamine responses and, like I said, I was having to manually scratch my throat from the inside because I was so allergic and itchy. Itchy eyes, mucus, scratchy throat, sneezing and stuff like that. I remember I got my allergies tested that year.

YIU: Before or after?

JAY: While I was living there. The mold spot on my leg blew up and took over my whole leg and down my calf. It was a huge histamine response during that time.

YIU: And you were a swimmer? You said that you were an athlete.

JAY: Yes. Not only did I swim often twice a day as a competitive athlete before school and after school and on Sunday mornings, I also worked at a pool. During the summers, I worked at the Kemptville Community Pool, I guess for about four or five summers, where the staff was also expected to do the pool maintenance which involved shocking the pool and treating the pool with chlorine and whatever else.

[00:08:09]

YIU: Wow. Okay, so it sounds like you were pretty young when you first had some signs of sensitivity and illness. What was your initial impression?

JAY: Um, I hadn't made a lot of connections between environmental exposure and even diet. I've always been concerned with diet but the other sort of big factor for me is that I also took Minocin (minocycline), an antibiotic for acne. I begged my doctor to put me on Accutane but he was a bit of a hippie and refused and I was mad about it. I was also completely depleted in terms of my microbiome and I wasn't making these connections in terms of how I was sacrificing my short-term health or appearance. I was sacrificing my health for my appearance in the short term. So, I don't remember your question.

YIU: What was the initial impressions, since you were seventeen and eighteen, and you didn't make any connection with MCS?

JAY: No, I didn't. I didn't know what that was at the time. By most people's standards, I was healthy and conscientious about health and things. I looked healthy but my health really was deteriorating. I long suffered this disconnect of how I appear from the outside and how much I'm struggling from the inside, but I didn't have the words to describe this and I wouldn't have identified as someone with chronic illness.

YIU: Right. And you do identify as someone with chronic illness now?

JAY: Absolutely.

[00:10:24]

YIU: Okay, before we move into that part, can you tell me a little bit about where you were living at the time when you first discovered your illness? You said that in your early twenties you got quite sick.

JAY: So I stopped swimming in my early twenties. I moved to Toronto in 2002. I had competed at a major swimming event and that was it. I just couldn't do it anymore. My skin was a mess. I was scratchy and dry. I also was diagnosed with celiac disease, which was a real moment for me and really marked a change in terms of obsessing over product labels and shifting towards a non-toxic lifestyle and replenishing my microbiome from years of abuse of antibiotics. So I was living in a relatively new condo building on Jarvis Street with my then-partner and still struggling with acne and things. But, during that time, I made a few important connections and started treating my severe cystic acne with diet and addressing the inflammation in my system and going initially wheat but gluten-free and dairy-free and noticing a huge improvement in my chronic fatigue and many things that I was dealing with. And that was really the beginning of figuring out why my body was reacting the way it was.

YIU: Yes, and what sort of things did your body start reacting to at that time and do you remember distinctly any smells or products that you remember at home and how they affected you?

JAY: My fragrance sensitivity came on pretty gradually. As you start cleaning up your life, you start to notice how things affect you. Like I did a really, really strict elimination diet. And I remember the minute that I brought honey back into my life. I went to this Florence market which I lived across the street from and went to the honey man and tried some honey on a stick and had this overwhelming saliva response where I couldn't contain the saliva in my mouth.

YIU: Yes.

JAY: It took a long time to be diagnosed with celiac disease. This was 2002 so there was just a different level of awareness about celiac, like you couldn't order a gluten-free pizza from Pizza Pizza to your door. So it took a long time and because my MCS was getting worse and because the symptoms of Celiac are so sort of broad and varied, I had people telling me that it was in my head. I finally had a doctor say to me, "Have you ever been tested for celiac disease," and I was tested. And then as soon as I got this diagnosis, I moved over to the care of a naturopath who really educated me on holistic wellness and put me back together. One of the things that he did was a chlorine cleanse, where I implemented a home sweating regime. And even though I hadn't been in the water at that time for about a year—like a hard stop on chlorine because I hated it so much. I was just scratching my skin off because my eczema was so bad—it was really traumatic

to realize how my body had been holding on to chlorine because I would get into the sleeping bag and turn up the electric blanket, and sweat and sweat and I smelled like a bottle of bleach.

YIU: Wow.

JAY: So I think that cleanses are important things but the psychological impact of cleansing is often not addressed. I just remember having these awakenings of like, “Oh my gosh, here I was, an athlete, again healthy by anyone's definition, but embalming myself with all of this poison.”

[00:15:47]

YIU: Wow. Okay, thank you for telling that story so clearly. So let's go back a little bit. You mentioned that you were living on Jarvis. I actually used to live on Jarvis and Glouster so this is fascinating. And it took a long time for you to receive the diagnosis of celiac disease and that was in 2002. And you described it as this real moment that marked a change where you shifted towards non-toxic lifestyle.

JAY: Yes.

YIU: So can you talk a little bit about how you have come to even discover medical treatments or doctors and medical access that you could receive at the time?

JAY: I guess I developed a lack of trust or frustration with conventional medicine because it had taken so bloody long to be taken seriously and to find this answer. I can't remember exactly why or who put it in my head or how I was even introduced to this naturopath, in particular, but it was a huge shift. I knew that I had broken my system down in various ways, and that I needed to build it back up and did that with the care of Dr. Simon Lo at the Toronto Naturopathic Clinic. So I knew that it was multifaceted and complicated and that I was falling through the cracks because I looked one way but I was another. I was consuming a lot of even Diet Cola, chemicals in many forms. So, it was complicated to wade through that. I remember it was a real period of rethinking everything that I had done from oral and topical pharmaceutical drugs for my skin to sugar-free “health food” to making the connection between cystic acne and the consumption of dairy and animal product.

[00:18:26]

YIU: So you mentioned that there's a real moment of shifting towards a non-toxic lifestyle. What did you begin by eliminating? You mentioned honey was one of them.

JAY: Oh yes, I had that honey reaction when I did the elimination diet and brought honey back in. Really it started with celiac disease, and reading labels, going gluten free. It's important for people with celiac to also be dairy-free. My naturopath also made me get off of these antibiotics that I was really stressed about going off of because, previously when I had even missed one pill,

I would break out in jawline cystic acne. It was completely traumatizing so I was really afraid of what my body would do without the support of these drugs for my skin. I remember feeling just blown away that because I had cleaned up my diet, it was okay for me to go off of the antibiotics. So that was so profound for me, the realization that dermatology and gastroenterology are one and the same. Cleaning up my life started with cleaning up my diet, and the rest of my awareness grew from there as a result. As I started to clean up my diet, my general sensitivity and awareness about the next step was gradual and it happened over time.

YIU: I see. So you talked about a long time of diagnosis, how long did it take?

JAY: I mean, there's such a thing as adult-onset celiac disease, but I had had a few intestinal issues in my teens. I guess through university, so 1999 to 2003. Like, I think actually, I said 2002, which is when I moved to Toronto, but I think my diagnosis was in 2003.

YIU: Okay, I see.

JAY: It was at least three years of really trying to sort of get to the bottom of why I was such a mess.

[00:21:08]

YIU: So you mentioned that you have developed this lack of trust with conventional medicine. Is it because of certain experiences that happened with conventional medical doctors, can you talk more about that?

JAY: I was so belittled and not taken seriously and sent to psychiatrists, which isn't to say that I didn't also need a psychiatrist, but it just took so long for them to help me, take me seriously, be thorough. I think that it's a crime the way that nutrition isn't emphasized by conventional medicine as the most important aspect of our overall health. It should be the first thing that we talk about, the first resource we use to improve our health. Diet is my religion. It's just everything to me. It's everything.

YIU: Okay. So have you ever brought up chemical sensitivity to doctors and how did they respond?

JAY: Yeah. I'm currently on a waiting list at Women's College Hospital to be seen by their environmental health team. I just got a notification last week that in light of all this, it's going to be another twenty months before I'm seen.

YIU: Twenty months, wow. And how long have you been waiting?

JAY: I've already been waiting about three years.

YIU: Oh, wow, how small is the team?

JAY: Exactly. Exactly. Two people dealing with this, so I don't even know. And I thought if things were different, if my financial situation were different, if we didn't have a pandemic going on, I thought about—because Silent Spring is featured in my film—and things were otherwise like, I would have loved to have said, “Hey, I would never want to take resources away from someone in a worse situation than my own. But I also would love to go down to Silent Spring and see what they have to say about my health.” Forgive me, I keep forgetting the questions that you asked.

YIU: Oh, I said, “So have you brought up chemical sensitivity to other doctors outside of the Women's College Hospital and how did they respond?”

JAY: Well, I recently switched family doctors because she was a pro-lifer and I actually wrote about her reaction to my request for an abortion in the Toronto Star, which is available on my website if you Google it. So, it was time for me. I should never have stayed with my family doctor for so long because it just wasn't a match for many, many reasons. She ended up giving me a referral initially to Women's College Hospital, but I could tell that she wasn't especially informed or sensitive to my plight, you know, but I couldn't get that referral from my naturopath. I needed it from my family doctor so I got it. I've since switched family doctors and definitely am with someone now who understands and is far more compassionate about this set of ailments and symptoms and he asked me savvy questions about also being sensitive to light, like to natural light to artificial light to technology to noise, all of which are true. I think I generally identify as HSP, highly sensitive person, overall. So, yes, I think awareness has grown. And I've also taken steps that I maybe should have taken sooner to just have a family doctor that takes this seriously and understands how crippling it can be and understands and empathizes with how it governs my daily life.

[00:26:03]

YIU: Yes. After the diagnosis of celiac disease, how did you first find out about chemical illness and chemical sensitivity? Did you do some self-research?

JAY: Yeah. I'm trying to think about the major aha moment there. And again, I guess it was just really gradual. One of the things that has always hit me is walking around in the neighborhood and being exposed to people's dryers and fabric softener and laundry fumes. That hits me like a wave and getting close to men and their clothing that had been washed in whatever conventionally scented product. And then because I'm a wardrobe stylist, I work in fashion, gradually being more bothered by the off-gassing of clothing when you go to the mall or when you open a new box of shoes or when, “Oh my god, now all of a sudden, all of these clothing brands have their own signature fragrance that's now for sale at the cash” and just feeling sort of gradually bombarded and encroached upon. The whole world seemed to be getting more toxic and I was being affected by it more. I'm trying to think of what year it would have been, but the



first time I contributed to the Environmental Defense Just Beautiful Campaign, which at the time, Environmental Defense was led by Dr. Rick Smith, who is a notable voice in the space and he is one of the experts featured in *Toxic Beauty*, so that I found really reassuring that Environmental Defense was taking the issue seriously of chemical exposure through personal care. There were experts out there really prioritizing this research and addressing the root cause of many illnesses, tracing it back to chemical exposure and the complete lack of regulation of cosmetics and personal care.

[00:29:15]

YIU: Yes, so I would really love to move to that, which gives us a nice segue to talk about your film. But before we move to that, you mentioned that you switched family doctors recently due to your doctor's denial of your healthcare request. So, what are some other experiences you had advocating for yourself as a patient?

JAY: I have countless.

YIU: Perhaps tell us some memorable ones that you've encountered?

JAY: I find that I'm constantly having to sort of educate and advocate for awareness of this issue. I do it more often in the context of like trying to use an Uber or trying to carpool with colleagues who insist on wearing fragrance to work in the morning. That's where I find I have to advocate more. But, in the context of dealing with this family doctor, she just was not respectful of my diet. I'm not entirely vegan, but I identify as plant-based. Even with modest use of marijuana or alternative medicines or CBD oil, she was horrified and disrespectful of those alternatives. We were politically at odds and she generally hadn't made a lot of important connections between diet and health fundamentally. So we battled on all levels. There were countless times where I would share with her what I'm doing and my opinions or beliefs or lifestyle were belittled or negated. Or I would suggest, "Now I'm dealing with that by going dairy-free," or, "I use CBD for that," and she would be horrified.

YIU: So you mentioned earlier that if your financial situation looked differently, things would be different in terms of receiving medical care. How do you think class, race, and gender intersect with your access to receiving health care and the reality of living with MCS?

JAY: Well, I know that there's programs available where you can go and retrain your nervous system to not go into fight or flight upon exposure, because it really is this full-body panic that I go into when I'm bombarded with a wave of poison. Sometimes, there's not a lot of compassion for that or awareness of that and it's a really alienating experience. Here I am on this waiting list. I don't have the money to go out to Victoria or the East Coast. There are many programs available, but they require that you pay for them and that you take a chunk of time off of work. And I know that, despite how much I'm genuinely suffering, I still enjoy a lot of privilege that other people don't. At least I have a degree of awareness—I've been able to make these

connections and navigate accordingly and control my exposure. I've been able to engage the other people in my building about switching everybody's laundry detergent over. I've just taken steps that a lot of other people are not taking—they are suffering with poor health, but not making the connection to the products that they're consuming. So I know that I'm suffering and I know that if I had the money, I would do more, but I also recognize there's quite a bit that I am able to control. I'm getting by and I really have a lot of compassion for the way that race, culture, economic status reduce access and worsen symptoms. We address that in the film, everything from Eurocentric beauty norms to the way that talc products are marketed to people of color. We know that ovarian cancer is higher in indigenous Canada because baby powder is one of those multipurpose products that you can use for a thousand things. It's available in stores and in indigenous communities, so women are using it. They don't know any better. Education and access aren't available.

[00:35:23]

YIU: Yes. And earlier, you talked about how you do self-advocacy in terms of asking for folks to shift their personal care products and laundry detergents within your building. Where were you working at the time when you talked to your co-workers about the personal care products? And how did that go? Do you have any advice or strategies?

JAY: Yes, let me tell you, it's a little easier now that I've released a film and there's a little bit more awareness and respect on some level. But I have had a close colleague tell me that my chemical sensitivities are all in my head. She also happens to be this Canadian spokesperson for CoverGirl cosmetics. She told me that it's all in my head and I really had to bite my tongue and let that one go. I'm sort of grateful, on the one hand, that I have a fragrance sensitivity because it makes things impossible for me to endure. But the reality is that we're all being affected by these toxins that are accumulating and entering our systems. Some people are more immediately bothered by it than others. It's not that it's not affecting you—it actually is, but you're just not aware of it. It's a canary in a coal mine analogy.

YIU: Yes. And at the time, were you working as a wardrobe stylist or have you moved on to making the film?

JAY: Well, I'm freelance so I'm always juggling many things. My income is dependent largely on being on a fashion set, which is getting increasingly difficult for me and just impossible. Part of my work involves sourcing and shopping and schlepping and being in a mall environment or rummaging around various places for clothing and supplies, being exposed to all manner of environments and materials and chemicals. And then the other part of my work is spent on set where I'm navigating walls being painted and hairspray hitting me in the face when I'm adjusting someone's collar. It's a really toxic work environment, and it's just becoming prohibitive for me. I've had countless conversations and luckily a lot of my fellow stylists and hair and makeup artists are bothered on some level too or they know enough about the risks that they're respectful of my sensitivity. They'll get me to hold my breath or they'll wait till I leave the vicinity. My

assistants serve to support my MCS. I'll stand between two fans when I work and I'll have a fan blowing away from me on either side. It's such a big deal for me, but it's often the first conversation that I have with a new stylist. It is so much better for me when I show up on a set and I know the team so that they know how to help me out. The role of my assistants now is to essentially help me do the job, but it largely helped me navigate chemical exposure.

[00:39:39]

YIU: I see. Can you talk more about how that conversation or first conversation looks like and you mentioned a little bit that the general attitude is dismissal?

JAY: Lots of times there is compassion but lots of times there's just complete ignorance. They'll say, "Oh, but I'm not wearing any perfume." I'm like, "Yeah, but you just put on this highly fragranced moisturizer on your hands and it's making me fucking crazy." They won't extend it to the fact: "Oh, well, but I just put on a little bit of aerosol deodorant." Like yes, it's everything, it's everything, it's everything. And people don't realize. They think that it's *just* perfume. Or people will forget and then I'll ask them again. Usually it's models like because I'll get to know the crew. We'll be booked on a job and maybe the first day is bad, but the next day they remember and that's better for me. But, most of the time it's models. I work with these models super closely and they'll just come in and do whatever and I'll just have to deal with it. People will completely underestimate the impact and how absolutely game-changing it is if you switch your moisturizer to an unscented moisturizer. A lot of the time, the conversation will look like, "Hey I don't want to impede your workflow and I fully respect what you need to do to do the job. Any unscented products that you can sub in, I'd be so grateful. I have severe MCS and it's like a laser beam to my frontal lobe. It makes me nauseous. It gives me a migraine, it makes me sweat. It makes my throat close, it affects my lungs. Anything you can do to help me out, I'd be so appreciative. But again, I'm respectful that you have a job to do as well. And I don't want to be annoying." If I know the makeup artist well enough or depending on the degree to which he or she is aware or respectful of the clean beauty movement, they'll say, "Oh, yeah, no problem. I have this in my kit." Or they'll say, "Hey, Sarah, heads up, I'm gonna be spraying," so I'll try to leave the room if I can.

[00:42:32]

YIU: So, some have accommodated your sensitivity in the beauty industry. Has your illness affected your relationship with your family or your friends?

JAY: I would say that my friends understand. My friends check in with me and if they're picking up a rental car, they'll go to the trouble of smelling 12 rental cars to find the best smelling rental car for me. Like my friends get it. But things like public transit, travel, meetings hit you in all sorts of different ways. You never know what you're going to encounter. If I find condos and buildings where there is cleaning of lobbies and elevators, that's really, really tough. But, aside from this COVID quarantine, I'm already a recluse. It's hard because everything can be hard,

even walking my dog at night. There are some nights where it's just a cruel joke that I can't even walk through my neighborhood and breathe air, because I've caught the neighborhood on a night where everybody's doing laundry. So I'm just like, "Fuck this. I'm just going home." I can't even walk my dogs sometimes.

YIU: Yes. It sounds like this illness has impacted your ability to access public space, but also, as you've mentioned, doing your job as a fashion stylist. Can you talk a bit more about how you navigate that and the difficulties of that?

JAY: Again, I hate to put anyone in the line of fire, but my assistants know and understand that there are stores that I can't go into. I hate to ask them to go in, but at least they don't have MCS. Because chemicals are dirt cheap and fashion is crumbling for a whole other set of reasons, a lot of fashion brands have gotten into the fragrance and cosmetic game. So now there are even more exposure to scents when I go to the mall or whatever. It's just constantly tough.

YIU: Yes. Before we move to the portion about your film, I wanted to ask if you have any relationships that you've developed with folks in an online community. I'm assuming that would lead us into the recruitment and the idea notion behind your film, too.

[00:45:51]

JAY: Yes, totally. I lean on that and I'm so grateful for that. And it's important for each of us to have community for our specific idiosyncrasies and whatever. There are a couple of people in the industry. I have one dear makeup friend, Jackie Shawn, who experiences the world the way I do. She has a clean kit, and if I'm stuck on a set with her, that's a best case scenario because we just understand each other and she wears a mask. She tries to take jobs that don't necessitate crazy hairdos with hairspray, but if she needs to use an aerosol hairspray, she just wears a mask, unabashedly. Definitely #MultipleChemicalSensitivity and #MultipleChemicalSensitivityAwareness and I love the movie Stink. The movement is growing. So at least the internet allows me to connect with people who experience life the same way. The isolation factor is real and I'm up against these obstacles. At my gym, after much negotiation, I got them to remove the automatic air freshener. At one of the studios that I would often work at, I spoke to HR and got them to take it down. So these are small victories. I'd love to have the conversation with Uber to at least be able to order a car. The interface should account for and allow you to make a request for a fragrance free vehicle. You should see my Uber rating because of the amount of cars that I cancel and the first thing I say to a driver is, "Hey, please cancel. Please don't accept the ride. Please cancel if you have had air freshener." They'll see my message, take the air freshener, throw it out the window, and then pick me up. I'm like, "That isn't gonna work. I'll barf in your cab like I already have motion sickness." People really don't understand that I will barf on you.

YIU: Yes, it seems like folks are unwilling to address this as an access issue largely as well, as you've mentioned in both the gym and the studio. So before we move to that, in terms of the

hashtags that you have mentioned, do you mean the MCS Awareness movement or the Anti-Toxin Beauty movement?

JAY: Both.

YIU: Right.

JAY: Because lots of people are pursuing a non-toxic lifestyle for many reasons, but having MCS is a different thing. Everyone benefits from non-toxic products. But when you suffer from MCS, you understand the immediacy and urgency on a whole other level so that that type of support is important for me. You need to find your tribe.

[00:49:40]

YIU: Yes. And so how did you find your tribe and how do you feel after finding this community of people who relate to you?

JAY: It's been game changing for me because it's so alienating and it was a moment for me to find Environmental Defense, to be included on the Just Beautiful Campaign, to be sitting around a boardroom and having discussions with different types of stakeholders and people from different backgrounds working on behalf of Canadians to create awareness and change policy. Even within that group, I don't know how many people would have immediately identified as having MCS. They would know the literature and they would know the impacts and people were coming from different backgrounds, but I don't even know how many people felt it with the urgency that I do. I emphasize feeling like you are totally paralyzed by something that nobody else even notices. I really can't emphasize how upsetting that is and how you inevitably internalize a weakness, or at the very least, an aloneness when everyone else is fine and you are not fine, like I'm not fine.

YIU: Yeah, you mentioned also in addition to that earlier that while doing the chloride cleanse with Dr. Simon Lo that cleanses have psychological effects that are often not addressed. Do you see a mental health professional or how do you navigate the isolation and alienation that you have mentioned on top of receiving medical treatments that are important but are also often emotionally taxing?

JAY: I am resourceful if nothing else, so I have made use of access that I have through Parkdale Community Health and have always done therapy when I can afford it, when I'm slugging it out in advertising land and have a paycheck that allows me to afford it. It's even reassuring just to search those hashtags and the community groups on Facebook just to read other people's experiences and know that I'm not crazy. I'm just sensitive and there are other people who are suffering. There are other people who are suffering far worse than I am. There are other people who have even less access or even less control or even fewer resources and it fuels that fire

inside me to really draw attention to the issue and have it taken seriously and to create data or content that substantiates why we need to take it seriously.

(Audio breaks)

Interview with Sarah Jay  
SESSION 2 (4/3/2020)

[00:00:02]

YIU: Okay, so now I want to move into talking about how you became involved in activism. I know that you mentioned when you come across air fresheners in places, you remove them, and then stick these stickers onto toxic products and public spaces as well as your work with Environmental Defense. So could you talk about how you first got involved?

JAY: In 2007, I started working with an NGO called Fashion Takes Action that is doing social and environmental advocacy to address fashion's impacts. Part of what we would do is produce green fashion events and we would try to be thoroughly and holistically green on all levels. In 2007, there were far fewer options than there are now, but we would engage clean beauty brands. By doing so through Fashion Takes Action, I was put in touch with Donna Bishop who is another fellow Torontonians who, at the time, had two locations of Green Beauty Salon and Spa. She would do the makeup and Brian at World's Salon on Jarvis and Adelaide would do the hair. I really connected with those guys in bringing to life these progressive fashion shows and it was Donna Bishop who said to me, "You need to be on the cabinet at Environmental Defense."

YIU: So in 2007, you met Donna Bishop. How did you get on to the Environmental Defense cabinet?

JAY: She was already on it and she brought me on. I started with Fashion Takes Action in 2007 so it would have been a couple of years after that, 2009 or 2010 when we started that work.

YIU: Wow. And so what was your experience when you first got to the cabinet of Environmental Defense? What was that space like?

JAY: It was amazing. I was so thrilled to formally align intention with action and bring more awareness to something that I feel so immediately. I became vocal in the space because I needed to advocate for myself and my discomfort has been my motivation to take this seriously. I joke and say my work has been about following my nose and being honest about the degree to which all of this stuff really affects me.

[00:04:01]

YIU: So you mentioned that when you joined on to Environmental Defense, you did both the campaign of Just Beautiful and Rethink Dry Cleaning. What are some of the processes towards developing such campaigns? And what was your experience of taking action on a scale of Environmental Defense?

JAY: Again, I was in there with people from different sectors, different stakeholders, different backgrounds. I was coming from a conventional fashion background and then had just aligned

with Fashion Takes Action to try and deal with the consequences of fashion that we were just starting to talk about in a pre-Rana Plaza world.

It was the first time that I really delved into the policy side of things and it really hit home the degree to which the government is not involved, the degree to which the government really pays the price when people are in poor health, what a disconnect that that really is, what's needed to get from A to B, and also being exposed to the extensive research that people are doing on multiple facets of this. And of course, *Death by Rubber Duck*, the book by Environmental Defense's then Director Dr. Rick Smith was super influential for me, who at the time was working on Canada's Next Top Model and Project Runway and these types of vapid makeover shows that weren't even measuring or improving what needed to be measured or improved. *Toxic Beauty*, the documentary, started as a makeover show that aims to lower your chemical body burden and blood toxicity and give you a green makeover.

YIU: Yes.

JAY: That format almost worked. Long story short, it eventually turned into a documentary. But yes, it was so validating to be in that room, having those discussions, realizing how big the problem really is, and the degree to which profit is constantly valued over human health. I was suffering for really legitimate reasons and this has everything to do with corruption and negligence.

YIU: Yes, so when you were talking a little bit earlier you mentioned your experience of working in makeover shows like Project Runway and Canada Next Top Model. What was it like working in a place that does use a lot of toxic beauty products? And would that conversation ever come up?

JAY: No, models and stylists, and people in general love their products, like they're so attached to their beauty rituals. It's such a personal and intimate thing and more is more for a lot of people. And so I was often just an anomaly in these contexts. Again, it was isolating but now I'm starting to stand up more for how uncomfortable it does make me. The nature of my work is shifting and I'm not on set as much as I used to be, but it was just totally alienating. I worked on shows called *Eat Yourself Sexy* and *Diva on a Dime* and all of these makeover shows. Necessity is the mother of invention and *Toxic Beauty* was born out of my frustration with the status quo and the fact that we are not improving upon what needs to be improved upon in these makeovers.

[00:10:04]

YIU: Yes. And you mentioned that you consider yourself an advocate of the Anti-Toxic Beauty Campaign. Do you consider yourself a community organizer at any point?

JAY: Yes, I guess I do by default. I've encouraged myself to speak up on my own behalf because nobody really was doing it. This is why it just meant so much to me to find



Environmental Defense, to find Dr. Rick and to really dive into that space. It just felt right. It was intention and truth aligning with action. I'm someone who ideally needs all of my hair combed in one direction, so to speak.

YIU: Yes. Can you talk more about finding that direction and how it feels given that you have found it?

JAY: I feel organized.

YIU: Yes.

JAY: I am a freelance person. I'm always fielding requests for various projects. So when I can focus on what really matters, it brings me clarity. I feel in alignment with what my body is physically telling me and the truth that feels really immediate. In that sense, sustainability and specifically the fight against toxins is a compass for me. Again, I feel like there's a lot of strength in vulnerability. I have been given the nervous system that I've been given, I have these chemical sensitivities, and I feel a sense of responsibility to sort of tell that story. I have MCS, and I'm aware of what these things are doing to me, but these things are affecting you too, even if you're not bothered by the scent of Tide laundry detergent.

[00:12:36]

YIU: Yes, can you now tell me a little bit more about how you moved on to the project of making *Toxic Beauty*, which took ten years?

JAY: Yes. I wouldn't have been motivated to spend ten years if I weren't constantly reminded of the need to do it. I wrote it as a makeover show. I was working for Cosmo TV at the time so the first set of people that I bounced this off of were my producers at Cosmo, who loved the idea. We were awakening to the Clean Beauty Movement, but it was still sort of ahead of its time and even if executives were personally in line or hip to the issue, the advertisers didn't have the products to sort of plug into the show and make it work. So the TV business model was flawed because of a lack of products and the beauty community wasn't fully there yet. Once upon a time, I was invited to the Procter and Gamble Beauty Awards, where my peers were being recognized for excellence in editorial or whatever. I had my lovely assistant, Marissa Schwartz, apply a soy tattoo to my back that read, "PNG Go Toxin Free." And we arrived late to this event that was held at the Curlew. Everybody was there and all of these event photographers and people that I knew noticed me. I just felt this buzz happen and I posed for a few pictures against this brand, Step and Repeat. Within about five minutes, the young PR girls came over and asked me to leave. I was formally dressed, I had Environmental Defense campaign materials in my clutch and I just said, "Hey, I work in the business. I'm not here to cause a fuss. I work in the space and am taking chemical exposure seriously. It is an important thing to do and I'm here to recognize my friends and if it's okay with you, I'd love to stay and peacefully have this message." But they

weren't having it and by that time, they called security and security escorted me out and put me into a cab. That was a moment.

I found my way to White Pine Pictures, which had done a couple of other of my favorite films: *All Governments Lie*, *Sugar Coated*, *Guantanamo's Child*, to name a few, which are all essential quarantine viewings. I had mentioned to them this stunt of mine, and they were low-key horrified. I mean they were experiencing my frustration, which is that people were into the subject matter on a personal level, but just didn't quite know how to execute this in the context of television at the time. So that was a moment. And I could see that they were wrapping their heads around how big and how difficult and how ubiquitous and how challenging this was going to be as a subject matter and how much money was coming at us in the opposite direction. So we eventually recalibrated and realized that the controversy against us in television works for us in the context of film. So I rewrote it as an episode of the nature of things, I rewrote it as a docuseries, I rewrote it by ingredient. I rewrote it by product. I rewrote this a thousand different ways, and one of those ways was as a documentary feature, and that's what ended up sticking.

YIU: Wow. And so this process of writing and rewriting—is it done by you alone? Or were you consulting with someone? How did you come to the different versions of this film?

JAY: It was largely me. It was collaborative to some degree with my development producers, bouncing things off of them, but largely I was the one who felt the urgency and I was at the creative hub of this. Also because I was tapped into Environmental Defense and Dr. Rick's research and I was the source for all incarnations of the film throughout development.

[00:19:20]

YIU: I see. So I'm sure you're very proud of your film, which has been featured in so many different reports across different countries, ranging from *Marie Claire* to *Vogue* to *Shape* to the *Hollywood Reporter*. Can you talk a little bit more about this achievement? Because earlier in our interview, you said that having this film out really changed a friend's perception of your claim to your reality.

JAY: Yes, I mean, she hasn't messaged me to say, "Hey, I've seen the film, congratulations." But she has sort of begrudgingly tagged me in things saying, "Now I hear Sarah Jay's voice in my ear and I have a couple more clean beauty products in my kit. Thanks." Just sort of joking about the fact that she has given me a hard time in the past and that she's becoming a bit more aware and getting on the bandwagon even in a minimal way. But, I think everybody who wants to write a book or make a film or release anything, we hope that your creative work speaks for you and is a leg to stand on. So I'm glad to have this out and feel like I've contributed to the conversation and presented a lot of this data in a way that people wouldn't have absorbed it otherwise. Essentially this film is *Death by Rubber Duck* in film version. It traces directly to the work of Dr. Rick Smith and I always wanted to put chemical body written testing on the screen and that's what this is.

YIU: Can you talk a little bit more about the audience you have reached? Have folks reached out to you after this film has released?

JAY: Yes. I've put a lot of sweatshop clothing on a lot of models over the years and talked to them about this lengthy process. Most of my community know that I've been working away on this gradually, so people were really proud to see it. People don't necessarily associate our industry with poor working conditions or being hazardous. Lots of times, we're in beautiful spaces with beautiful catering, and we're well paid but the reality is that stylists and models have higher exposure.

The film opens with Rose-Marie Swift, of RMS Beauty, talking about the fact that her medical team immediately assumed based on her test results that she worked in the beauty industry. It's been meaningful for me to get messages from models saying, "Wow, I had no idea" and "Wow, what would you recommend". And it's meaningful to be tagged by beauty bloggers who have full lashes, full nails, full hair, full everything, have their minds blown and to be that first point of reference for them in their awakening and to see them communicate with their communities like, "Oh my gosh, I just saw this film. I've got to rethink everything that's in my kit."

YIU: Right.

JAY: And start to make those connections with health issues that they may be suffering from.

[00:24:09]

YIU: That's beautiful. That seems like you're creating a particular conversation at a significant moment and intersection. Besides your own experience, was there a significant moment or event or someone in particular that inspired your activism?

JAY: Oh, yes. Dr. Rick. But I will also say my friend, Donna Bishop of Green Beauty, who had a son that was diagnosed with cancer at under two years of age and she made the change. That's what I find is true of the leaders in the space, like the issue becomes very personal and they take it upon themselves to make the change. A lot of clean beauty entrepreneurs have gotten into the business because they got sick and they wanted to do it better. Lots of Queen Beauty Entrepreneurs and Dr. Rick Smith would be my inspiration, and obviously Rachel Carson.

YIU: Right. So now that we have talked a little bit about your achievements both on this side of Environmental Defense, but also on this film that you have produced over the course of 10 years, do you currently have any creative projects or activist projects that you're working on?

JAY: Yes, I'm working on a nail salon initiative to specifically address the impacts on nail technicians who are—

YIU: Yes, that's interesting.

JAY: —suffering from recurrent miscarriage and reproductive cancers. It is culturally sensitive and it's one thing for us to swoop in and have our nails done once a month or every couple of weeks, but we have to recognize the position that we're putting technicians in. People who work in the beauty industry are at risk. I'm sure we all know a hairstylist who had to stop being a hairstylist because their hands were just raw from chemical exposure. It was super impactful for me as a kid. One of my friend's mom died really early and she was a hairstylist. I always think about her exposure and how her life might have been different. Her name is Brenda O'Neill. I think that it's not just about us, it's about thinking about the position that we put other people in when we seek out these beauty processes.

YIU: Yes, that's wonderful. We're also trying to recruit and are working with California Healthy Nail Salon Collaborative.

JAY: Yes.

[00:27:51]

YIU: In terms of, this statement that you just talked about, "It's not just about us and our bodies, it's about a wider network of community," which you do talk about within your film, this collective impact of exposure. Can you talk more about how you think the future of the associations we make between scent and capitalism will or should change?

JAY: Scent and capitalism? Well, I ghost wrote a book called Eco Renaissance that is formally by a Green Eco Printer named Marci Zaroff. And there was a statistic that I came across from a California-based newspaper about the hard costs of fragrance being 1% of the retail. Everyone and their brother has a beauty brand. Every celebrity has a fragrance because these chemicals are dirt cheap. If they were of quality and sourced ethically, they wouldn't be so dirt cheap. And the density of this marketplace is precisely because all this shit is so cheap. I wish that people understood that products are designed to appeal to you on a store shelf. They are designed to perform in the short term. They are designed to be shelf stable. Especially in the fashion space, thanks to the horrors of Rana Plaza and everything else, because of the human rights sort of component in fashion, we're looking at those supply chains a little more. But the lack of transparency in beauty is horrendous. It's not a toxin issue, but it reinforces the general truth that beauty is unregulated and it reinforces the truth that we have no idea what we're ultimately applying.

I'm doing a personal research project on the cosmetic industry's persistent use of shark liver oil which is an ingredient called squalene that can be sourced from olives, sugar, corn, amaranth, wheat. It can be made biosynthetically, but it still largely comes from the livers of sharks despite a general awareness of how vital these creatures are to oceanic ecosystems. It's cheaper than plant's squalene because it occurs so densely in the livers of sharks. We're still largely using it

and nobody's talking about it. There are lots of ingredients that can originate from different sources but source disclosure isn't mandated on product labels. So I really have found my heart in the intersection of cosmetics and conservation.

*Toxic Beauty*, for many reasons, had to center around human health impacts. We couldn't go into the conversation of oxybenzone and coral reefs. We couldn't go into palm oil, deforestation, orangutan habitat. We couldn't go into micro plastics, we couldn't go into siloxanes, we could all of those things that in my ideal version of the film, we would have holistically addressed. We only had ninety minutes so we had to focus on human health and hone in. But I'm passionate about how this shark research that I'm doing drives the same point home that we have no clue. You have no clue, and cruelty-free Leaping Bunny, Vegan, those logos that brands pay for, they are given based on the payment of a licensing fee and self-assessment. You disclose your ingredients lists and you get this logo for your product. That isn't industry regulation and that isn't a cosmetic standard, that is a trademark and there are no legal definitions for the word vegan or cruelty-free. That angle will really resonate with another set of people. They will feel that injustice with urgency and I'm really passionate about that. Hopefully after this quarantine situation, I hope that we're going to return to a greater respect for the preservation and repopulation of biodiversity. Addressing the hidden impacts to species is the type of sustainability consulting and research that I want to do moving forward.

[00:34:19]

YIU: Yes.

JAY: It's a transparency issue. It's not a toxin or immediate human health issue. But I like how it's a complimentary and related issue that reinforces the same point.

[00:34:35]

YIU: Right. I think that this comment on the lack of transparency and the structures that have allowed it to happen is very important. And you have described your interest in locating in the intersection of cosmetic conservation. And you mentioned a little bit about the fact that we need to think through more of how as humans, we need to be respectful to interspecies relations as well. You talked a little bit about sharks. But what do you think needs to happen in order for the cosmetic and beauty industry, including fashion, to think more about the transparency issue, but also these damaging effects to both the planet and the bodies of people?

JAY: I think governments are turning a blind eye. I think all of this is far too much for individual consumers to navigate. And governments are profiting. Something that I wish we had more directly reinforced in the film is just a flowchart of these big chemistry brands and where the money is coming from and where the money is going and just the hypocrisy and injustice of Avon and Procter and Gamble sponsoring cancer initiatives, but simultaneously selling products that are linked to cancer and all of that bullshit. I think that regulation has to come from the

government. I think that governments need to listen to scientists and look at the science and really make the connection that, “Look, when people get sick, you're paying for it anyway. We're paying for it anyway.” So we need to address health more holistically because right now we're going around in a circle and it's a vicious cycle. We know about Health Canada and the FDA, we know about the precautionary principle, we know that any old thing can be put into production and go on a store shelf. In very few cases do these governing bodies lay the smack down and take something that is known to be harmful off of store shelves. That's why I'm super proud of when *Toxic Beauty* had its American release. Within days, the journalists latched on to *Toxic Beauty*. Of course, the talc issue had been addressed in the media many times before. But on the heels of *Toxic Beauty*'s American release, journalists latched on and really put the heat on the FDA and the FDA recalled talc in the States. I'm proud of that. And I think we need to see more of that. Concerned consumers can use EWG or Think Dirty or whatever else, but that's not enough.

YIU: Well, thank you so much for telling your story today Sarah and for sharing the journey into producing your film *Toxic Beauty* which folks can actually find online on both Apple App Store and Prime Video. I just wanted to end by asking you, if there's anything that I haven't asked today that you would like to share with us?

[00:38:34]

JAY: To reiterate, the causes, definitely the mold exposure at the Anglican Rectory in grade twelve, chlorine overexposure from being a swimmer, treating my acne with pharmaceutical drugs, and fully binging on beauty products all my life, like being that kid with every color of hair and just binging on it and loving makeup and going for it over many years. I will say now that I'm dating, I have a note in my phone because I got sick of writing it so bloody often: “Hey, just wanted to mention, I suffer from something called MCS. If you could avoid any products, you know, blah blah” and then flirtatiously ending with “The dirtier you are the better. Haha sorry to be annoying, but it just prevents me from getting close to you.” So it affects dating.

YIU: With dating, I would love to talk more about that. What is the experience of dating like when you do read that or send that message to people? Are you sending it on Tinder? Text?

JAY: Yes. All of the above.

YIU: Yes. So what are some of the reactions that folks have had? And when you meet with them in person, are they respectful of the boundary that you have set?

JAY: Yes, most people's responses are initially accommodating or like, “Okay LOL” or “Sure, no problem” or “Yes, I'm a neutral smelling person.” But then you get them in person and they think they've done you a favor by not putting on Axe Body Spray but meanwhile, they're off gassing on every other level and I can smell their hair and their armpits and their fabric softener

and every other bloody thing. So, people have nice intentions, but because awareness is sort of lacking, it still ends up being an issue.

YIU: You mentioned that you were living on Java Street with your previous partner. At that time, were they accommodating?

JAY: My relationship with that partner didn't ultimately last. I was going through so much at that time and we had been swimmers together and then we were transitioning professionally. He was a paramedic. We ended up breaking up around that time. So that whole time was a bit of a mess. But it is astounding to me—I have friends that work in medicine or as paramedics and the degree to which they don't connect these issues with health and wellness. Or they're still using hand sanitizer full of triclosan and fragranced Lubriderm and their hands are like raw and they just accept it. They just think, “Oh, it's on a store shelf.”

YIU: I see.

JAY: “Hand sanitizer is in a hospital, we need this. It's safe. It's healthy.” Some people just get lazy or aren't uncomfortable enough to just seek alternatives.

YIU: Yes, for sure.

[00:43:09]

JAY: Talking about what I use for menstruation and what I use as birth control, those are other conversations, but I don't use hormonal birth control. I use something called the femme cap, along with a product called contra gel. And so that's a thing, talking to new partners about, “Okay, well, here's what I do,” and “No, I don't want to use that,” and “If we use a condom, I have these.” Sometimes I can laugh about it easier than others, but sometimes it will take a lot of energy for me to ask for these accommodations. Then I'll show up, and they will have forgotten or I'll show up, and they'll say what the Uber driver says, “Oh, I took the air freshener out.” If you have your window down, I can smell you a block away. That will seem just crazy to some people and then I feel self-conscious about just coming across as high maintenance, when really I can be chill on some level. I will have expended a lot of energy with my initial introductory speech so then it becomes really hard for me to say it again, or it'll be easier for me to say it in a text. Then if I have to reiterate it in person, sometimes it feels more awkward and then I get upset with myself for not speaking my truth and not being an advocate. But I'll just be so exhausted by it all. They'll suffer through it and then I'll be on my couch for a couple of days with exposure symptoms.

YIU: Right.

JAY: Yes, it's a lot to navigate. Economically, I am talking to my new lovely doctor about having MCS considered as a disability because I can't work. I can't work on a fashion set anymore.

YIU: And how's that going?

JAY: Well, I just switched doctor so we have a lot of a lot of things—

YIU: To catch up on.

[00:45:35]

JAY: Yeah, so that's worthy of note. I will reiterate that it's amazing how much less alone I feel by reading the experience of a stranger who has MCS. I'm really grateful for the way that many of us have sought community online for various things. Working is a nightmare, we've talked about that. I need a lot of downtime and alone time and recovery time. My regular workflow is gearing up to being in public and being on set. It's tough because at a lot of dress up events, people pour on the chemicals. Formal events and dress up events are part of what anyone working in fashion has to do, and those are especially difficult for me because people pour on extra chemicals. I will add Erin Brockovich to Rachel Carson and I mean, even Naomi Klein. At least I know that Naomi Klein sort of has made a few more personal connections to her personal regime. I have been meaning to reach out to Erin Brockovich and say, “Girl, I'd love to be your stylist over here and give you some tools and some alternatives for cleaning up your own regime and being more in line with what you're doing, professionally.”

YIU: Yeah, actually to end, would you like to tell us some of the products that you do rely on for personal care when folks ask you for advice?

JAY: Yeah, it's hard knowing what I know to recommend any particular brands because of the way supply chains work, like a brand can be thinking they're doing everything they can, but toxins or sharks or whatever still end up in their supply chain just by nature of the supply chain. So it's tough for me to give brand recommendations. But I think that in many cases, smaller and local homemade brands have a lot more control over their supply chains and what's in their products than the big guys. And I used to be the person who would have a carry-on sized bag just dedicated to products. Like my product dependency used to be so high and I needed all of them. Now I don't operate that way, like the oil that I use as a moisturizer is also what I use as a makeup remover and I prioritize multipurpose things and I shower a lot less. I wash my hair a lot less. I actually don't even wash my hair; I use baking soda and water and apple cider vinegar as a conditioner. I have a fragrance free bar soap because I'm also taking seriously the degree to which personal care has a plastic problem. So refillable products and products packaged in glass or paper over plastic for sure. In terms of cosmetics, I do use Sappho cosmetics which have the most phenomenal mascara. I use Sappho eyeshadows, I use RMS foundation and mostly stuff that I get at the detox market.



[00:50:19]

YIU: That's really helpful. Thank you, Sarah. I had such a great time speaking with you. And I'm so thankful and grateful for your patience and the insight that you have shared. I can't wait to share your film with others that are in the US that haven't heard about.

(End of April 3, 2020 interview)