An Interview with Chloe Durand; June 15, 2020

Kim

All right, Today is June 15, 2020. The time is 10:18am. This is Kelsey Kim speaking with Chloe Durand for the Center for the Study of Women. All right, Chloe, thanks again for joining us. Can I just start off and ask when and where you were born?

Durand

I was born on February 17, 1965 in the Pas, Manitoba, Canada. I was born in a pulp mill town.

Kim 2:52

What was that like?

Durand 2:55

I guess when a vehicle goes by, it's hard to hear me. [laughs]

Kim

Oh, no, it's fine.

Durand 3:01

I was born in a pulp mill town.

Kim 3:06

What was it like growing up in a pulp mill town?

Durand 3:11

Stinky. I was sick. I was sick a lot. I was born two months premature. I had an identical twin sister. She died within the two months after we were born. I was supposed to die too. So I'm just wondering if being premature, being born in a pulp mill town and then I found out apparently when my mom and dad were living in a building where the house had flooded, all came into play, and I have mold issues. As well my mom was given some kind of drug they gave pregnant women back then. Can you hear me?

Kim

Yeah, I can hear you okay. There was a little bit of, it sounded like something might have passed by but I can hear you. Yeah, and what did your parents do?

Durand 4:04

> My dad is an electrician and he worked as a plant technician in telecommunications, with all the electronic type things. He had a room filled with all these electronic things at work and at home. He also owned a TV shop for awhile. My mom was a housewife and she worked for my dad and had other jobs while growing up. And she's really sick too. I’ve been sick with MCS and mold exposure, but so many people including my dad has a hard time understanding.

Kim

> Oh okay, so your mom has sensitivity to mold or chemicals.

Durand

> Well, she does. I know that recently she just purchased some information about a mold diet. [Interview from 4:20-7:50 has been embargoed].

Kim 7:49

> I see. Did you have any other siblings?

Durand 7:51

> Yeah, I have another sister and a brother. I think they might have a couple health issues. My sister is healthy. I think my brother has a few things wrong. I am unsure if he would ever admit any of his health issues were due to the environment.

Kim 8:06

> Oh I see. Are they older or younger?

Durand 8:09

> My brother is six years younger. My sister's a year younger. And my brother has had mold at his place. I don't even talk about mold exposure and what and how it could be affecting them anymore, because what’s the use anymore? I tried. I don't even really see them anyways because they're scented. And they can’t seem to bother to be unscented so I can't even see my family. My mom did her best to have the household scent-free, and my dad was very disgruntled in the beginning. My dad continues to do certain things such as burn a paint can of oil within a couple feet of my tire of the van while I am in the van. It seems like he is trying to get a rise out of me. I don’t say anything anymore. He also gave me a dandelion that was sprayed with some chemical. I felt like crap. I didn’t say anything at the time as I was not sure how to approach it. Sometimes it’s not worth the effort. [Sentence has been embargoed]. Like I say it’s not worth the effort on my part to participate.

Kim

I see. So it seems like mold has been a pretty big issue in your life.

Durand

Yes. And even when I lived in residence at university. Oh wait, wait when I was sixteen-ish around there, I remember mom and dad went to the lake and the house basement, the water started coming in through the window wells. And shortly after, I started having my period, I was really sick and then I ended up with endometriosis. And I was just getting sicker and sicker. I had no idea what it was, no idea. But maybe before mom and dad even moved into that house it may have leaked in the basement through the window wells. And then when I lived in university residence in the ‘80s, there was always water tubbing, shit showers as they called them, and so it smelled like a skunk in there. They eventually tore the building down, but they didn't say anything had to do with mold from what I know of. I am sure that mold was a big factor.

Kim 9:49

And you mentioned something about university.

Durand

Oh wait, cars going by.

Kim

Okay.

Durand

Can you hear me?

Kim

I can hear you.

Durand

Sorry can you repeat that?

Kim

Oh, you had mentioned something that happened at university?

Durand 10:09

Oh yeah, when I lived in residence. People were always throwing people in tubs, getting water all over the place. You sit on a toilet seat, and someone would throw a bucket of water over your head, which was called a shit shower, and you would slide off the toilet. Or they'll put leaners on the doors; which is when you open your door and the bucket that someone leaned against the door all filled with water leaned in and the water poured all over the carpets. Then the carpets were all wet. It was so bad in there, it smelled like a skunk.

Kim

Oh, I see, like a lot of like mildew.

Durand

It smelled like a skunk. And they finally tore it down a few years ago and built a new residence. I think I heard that it was torn down because it was old and I would one hundred percent say mold is a big factor and am glad they tore it down and built a new dorm with stricter rules. However, I have only heard it was torn down because it was old.

Kim 10:57

What university was that?

Durand 10:59

University of Manitoba.

Kim

Oh okay. Yeah, so were there any other issues while you were in school? We can back it up a little bit to talk more about like elementary through high school. Did you have issues with mold or being sick at the time?

Durand 11:20

Well, I did have a hard time learning new things and studied hard. And I was always tired, I know that I felt grumpy and irritable a lot, but I didn't know why, well I shouldn’t say grumpy is the word, because I was always being blamed, well who wouldn't be irritable, because then I was getting blamed for things I didn't even do, right? So of course I'm always talking back saying I didn't do it. And then when I say that, well it's, “Yes, you did” and it’s like okay, whatever on my part. So anyways, I was sick a lot. I remember in grade one. I had to go from The Pas to Winnipeg, Manitoba, like probably an eight-hour drive south at that point, I can’t remember, because it was the long road to get there. Since then a shorter route has been created and drivable. And they did something to or with my bladder, I can’t remember what they did. So I've always had bladder issues and even a few years ago, they were going to remove my bladder, or give me a pacemaker for my bladder—InterStim I think it was called. And thank goodness Social Assistance Disability screwed up, because really it was my environment that was exacerbating the issue. So if I'm in mold initially or a lot of cell phones or electrical, perfumes, etc. There's so many factors, it would feel like—still feels like—I have a bladder infection, holy crap. It's like, I could have had my bladder removed for nothing. The issue with Social Assistance Disability was that I could not stay in the hotels or accommodation they had in mind. I would have had to go from Manitoba to Ontario to test to see if my body would accept InterStim. It was dangerous and could be life threatening if things went wrong. Social Assistance Disability would not agree to the terms where it was best if I stay there during the testing time. Social Assistance Disability figured I was to come back and risk my life. Anyways, long story and it never happened. As well if there was anything that went wrong with this InterStim I would have had to been transported directly by air to Ontario as no one in Manitoba did the procedure at that time. It was very frustrating. It was something that raised more red flags with disability. Another accommodation request they couldn't accommodate. I feel that having to ask for accommodation in an emergency would have been a nightmare.

Kim

Yeah. And just continuing along this line of talking about childhood and schooling, we're also kind of wondering about your social life growing up. So were you able to hang out with friends? Did you do extracurricular activities?

Durand 13:00

I was in every single extracurricular activity you could think of. In high school, I was an honor student studying my butt off and I was in basketball, floor hockey, volleyball, badminton, chess club, string art club, French club. Whatever club or activity you could think of I was in it.

Kim

Yeah, that's actually a lot. And a lot of sports too. Yeah.

Durand

Yeah, well, that kind of ended but yeah [laughs].

Kim 13:32

Were there any health issues while you're doing all these sports and extracurriculars and like honor club or were you generally for the most part, okay?

Durand 13:45

I still didn't feel that great. I just pushed myself because it was, like I felt my parents expected so much out of me. So I did everything I could to have the best marks and achievements. So I just did everything I could, and I had to do everything, I had to be perfect. I mean, I wasn't but you know what I mean? I had to do everything to perfection and holy, it was so hard, it was. I was continuously compared to my sister. And then my friends; I realized I always got teased in school, I never really had—the only friends I had were the ones who were the high mark nerdies which apparently I guess I was in that group. And so, [unclear] someone who wasn't really my friend would sit beside me and cheat on an exam and pretend to be my friend [laughs]. So I think I hung out with a couple people. I was bullied a lot in school. I did a lot of studying and when I was sixteen, I started working. I think maybe age sixteen. I started cleaning up mom and dad's TV store, but it was kind of hard because I felt like I was getting picked on by them. My sister also cleaned the store as well. I finally just quit that job because it wasn't worth the stress. So then I worked at the theater, a local theater for a couple years. Kind of as a rebel according to my family, sort of not really. But I went to some parties and stuff when I was sixteen and seventeen. And then I quit going to any parties really. And then I went to one grad party, big mistake. And in grade twelve, I was the best student you could think of.

Kim

Oh, wow, that's incredible.

Durand

Yeah, I didn't get honors in grade twelve but I really studied hard. And I remember one exam, one math exam the year or so earlier where I got three percent; so all I can think of was I was reacting to something back then or something but the reason I got three percent was they couldn't understand my handwriting in my math exam. So, I took the course over again in my sister's grade, just that one section, and I aced it the next year with almost one hundred percent on the exam. So it was just my handwriting. And also I remember my dad, okay so I would go down into the basement, my dad had all this electronic equipment. I couldn't understand math some days. Dad was a genius in math and he would try to explain it to me. And then I would just be crying and crying because I didn't understand it. And he would say, "You're smart, you get it, you understand it. You understood it a few minutes ago," or whatever he used to say. But maybe because I was around all the electronics when I went to the basement for help, and then there's the mold stuff, I think it all messed with me along with fragrances. It's hard for someone to understand who doesn't have the symptoms—it would seem confusing.

Kim

Yeah, it seemed like you really excelled though in high school despite some of the health issues that you're having.

Durand

Yeah, it was hard though. Even in university. I had surgery upon surgery in university. The year I missed the most work in university I made the Dean's honors list. I received a scholarship that year. I studied my ass off. I offered to buy notes from people and they thought I was just skipping class. More often than not people would not let me buy nor give me notes. I am thinking, it’s like, no, I'm just sick. The funny part was that when one of my fellow classmates found out I received the scholarship. Oh, was he mad. He made a big stink about it and stomped out.

Kim

What kind of surgery did you say you had during university?

Durand

Okay, well, [unclear]. Okay. The first one was like age eighteen or nineteen, right before I went to university. I had surgeries for bladder stretching, interstitial cystitis, endometriosis and more. And then finally at age forty, around my birthday, I had a hysterectomy because I was constantly bleeding, bleeding, bleeding, and it wouldn't stop. I had my right thyroid removed, a hemithyroidectomy, in 1991. I had a tumor in my thyroid. So that was like, see I had graduated university in ’88—well, I think it was done in ‘88. And then the graduation was ‘89. I had to take an extra half a year of university because the lab technician lost all my work in my cartography class on the computer, so I had to drop some courses to finish that class. And then that summer, before the last semester, I got bit by a tick so I had mono right off the bat. I didn't know that was any relation to being bitten by a tick. When I started doing research in the past few years about chronic inflammatory response syndrome [CIRS] and all my health conditions and mold and Lyme, I looked at the conditions people were diagnosed with and realized, that's my life. Right after I got bit by a tick, I got mono.

Kim 19:34

Oh, no. So it sounds like even though you're having these health issues, you still were able to do really well at university. Dean’s honors and everything so.

Durand

Only one year.

Kim

Oh, well, that's still something.

Durand 19:51

Yeah. Oh, and first year of university I started out in commerce. And the professor took me aside and said, maybe I should drop all the courses before he failed me. So I switched from commerce to human geography. So I keep telling everybody now that I'm a stat of what I studied; I studied birthrates, death rates, diseases, population control, and then I did some research and a paper on the impacts of people on the environment and the environment on people in my tourism class and I was in cartography class as well.

Kim 20:17

Yeah. And what did you do after university?

Durand 20:20

Well, I worked at—oh, during university, I worked at campus police, I was a student security guard. It was fun. We did a lot of stakeouts, and then there's just little ol' me, five foot nothing, catching people drinking. But I always gave them a chance. If they were respectful to me they could drink the beer on the spot. If they were rude and nasty I would confiscate it. But anyway. And then I worked at Tourism Winnipeg right after university. Also every year in university, I always had a different summer job. My last summer of university I worked at campus police and Travel Manitoba. I pulled a twenty-eight-foot trailer in that last summer promoting Manitoba tourism in Minnesota, North Dakota, South Dakota and Manitoba at the local fairs and exhibitions. So right at the end of the season, just before my first class back at university, I got bit by the tick so it was crazy and I was major sick and lethargic and all I wanted to do was sleep. After I completed university, I worked at Tourism Winnipeg on a temporary basis because they were only hiring for a couple months. After Tourism Winnipeg I worked at the Canadian Automobile Association, where I held several different positions and just kept going higher up. The pay wasn't any better. And then in '95 I had to quit because I was just too sick and they couldn't or wouldn't accommodate me and the staff thought it was pretty funny. The staff complained when I was allowed to work at home. Management put an end to that. I got more work done at home than at work. I was doing research, editing and updating the roadmaps that were sent to AAA head office in Florida. I would receive letters of excellence. The fellow employees would put nail polish on and blow the fan in my direction and it was one of the worst things. Oh, they were so mean. Well, they were even mean because well at that point, I could eat things they considered fattening. They did not like that at all. They were upset I did not gain weight. They were on diets. I ate a lot of food. This offended them. Any food I ate, even diet food offended them.

Kim

Yeah, sounds like they weren't very accepting or accommodating.

Durand

No, no, and I tried filing a human rights complaint. And the gentleman who was representing me advised me to keep going, keep going, but they were playing so nasty at the place where I worked. I couldn't do it. I was just too sick. So I had to drop the human rights case to keep my sanity and what was left of my health. The Canadian Automobile Association had to have some kind of training course I think on how to accommodate people with disabilities.

Kim 22:39

So what did you do after you left that job?

Durand 22:42

Well actually I started a business, a home-based business in reflexology and therapeutic touch. Because I thought, well, I will be able to control the things coming into my environment, but that didn't quite work either, because people were still scented and brought in pet dander, etc. So then I had to quit that. I had several short-term jobs that paid way below minimum wage and found out I could not tolerate the environment again and became even sicker. My mom and I created a gluten-free, wheat-free, yeast-free cookbook back in the ‘90s, and then we sold them to places such as the Celiac Society and local health food stores. We didn't really make any money. There weren’t really any of those type of cookbooks out there at the time. So we just made one.

Kim

About twenty years ahead of your time.

Durand

I know. And then I ended up in this car accident which was the final straw before I ended up having to file for disability. It wasn't even my fault, it was just really what got me. So I went on disability and ever since, I have been struggling and looking for housing. I had a car at the point I applied for and was accepted to receive Social Assistance Disability. It was too hard to take the bus and disability made me give up my car and move from the one indoor place I could tolerate to a point to make it work as good as I could at that point. And since then I've been on the move, since like the year ‘99, or 2000, I'm always moving and stayed in a couple places back and forth. I think ten years was the longest I stayed in a place. I just had to leave because they were spraying pesticides, and there were too many scents, paint, cleaning chemicals, and carpets, and so much more. In 2016 I left everything I owned due to mold. In testing in that dwelling, it was found that there was E. coli and fecal coliform and several types of mold, [unclear] in my place, because it was leaking urine and feces behind the wall from the neighbor above the whole three years I was living there. The landlord didn't even have to do anything about it. They had too many connections higher up, it didn't matter what help I sought, I had no recourse. He had connections, they had connections, so whatever. I left it all behind, basically. Well, I mean I kept a couple things like the hard drives that I'm finding out still create rashes and infection-like symptoms. I haven't transferred all of the information over from all the hard drives yet. This was in 2016. I would have thought things could have been fine with the hard drives in 2020. And I touched a cord of one hard drive the other day and I got like, infection-like symptoms—like holy crap, that's like, well, maybe four years later, in 2016. Yeah. But only kept like a couple things. And it's not even worth it. The pain, holy crap.

Kim

Yeah. So can we talk a little bit about how you realized that it was MCS or that it was the mold in particular? Was it like an official diagnosis or was it something that you did your own research for?

Durand

Okay, so, back in the ‘90s, before maybe around the time when I quit my job—I can’t remember the dates—I was sent to an occupational-type medical doctor that kind of dealt in Environmental Medicine. I have heard that this medical doctor really doesn't support people with MCS or people who have reactions to scent. I am unsure why he's keeping that medical doctor title for the province. But I hear a lot about him. I went to him, and apparently at that point in time, he thought I had environmental issues. He said something about Nova Scotia and I'm like, how am I ever going to get to Nova Scotia? So I didn't even know what he was talking about at all. I didn't even know that that was a diagnosis. So anyways, I'm not sure if it was the ‘90s or early 2000s when I saw him, I can't remember. And then, a few years later, I mentioned to my doctor that I found something in the disability library or something somewhere in Manitoba referring to multiple chemical sensitivity and like, holy crap, that's me. So I asked my doctor if she ever heard of multiple chemical sensitivity. My doctor said that’s what I have. I’m thinking like, thank you for telling me. She started writing letters including MCS after that point. But apparently, there was a human rights case going on in Manitoba at the time, where I can't get into too much about that. But I can get into the part I’m aware of through hearsay, where the doctors were not allowed to diagnose—it was mentioned to me at the time there was something going on. So my doctor was now writing down MCS in medical letters, but she said I had to go and get assessed in Nova Scotia as she was unable to provide me the diagnoses. So I did go to Nova Scotia, and travelled from Winnipeg by plane with the accompaniment of my sister, to the east coast of Canada to be assessed and receive a proper diagnosis. I came back to Manitoba and couldn't get treated. That was like 2011 when I got the actual diagnosis from them, 2011 or 2012, I can’t remember. When I came back to Manitoba I was still unable to be accommodated. I was advised that I needed magnesium IV injections and I still couldn't afford them. Manitoba Health said no to my requests for help. If I were living in Nova Scotia at that time, the costs would have been covered for the IVs. It also wasn't covered under my Social Assistance Disability. I went on disability in like 2000 or whatever and yeah, it's been quite a fight and a continuous search for housing. I continued to keep on moving and searching for a place to live. Government Housing could not accommodate me. I could not afford what I needed to create an indoor environment to have a better quality of life. I was bedridden for a period of time as well. And then 2016, okay, so I've always been sent to a psychiatrist, you know how that goes when it comes to the mold and MCS. My psychiatrist referred me to a medical doctor who practiced the Shoemaker Protocol which was for Chronic Inflammatory Response Syndrome. Mold exposure and possible Lyme were the main concerns along with MCS and other medical conditions. I was referred to different psychiatrists in the past who did not believe in MCS and continuously prescribed medications. I could not tolerate the medications and I knew that mental health was not my issue. My last psychiatrist looked at the past diagnoses from other psychiatrists and over time realized it was my environment affecting me. He was the only doctor that would meet me outside and accommodate me. He did so around the time I mentioned something about something scented he wore one day. A few times he said, “You don't need me,” and I go, “Oh yeah, because you're my only supporting doctor.” So he tried to refer me to see a doctor in another province that deals with the Shoemaker Protocol for Chronic Inflammatory Response Syndrome.

Kim 29:19

What is the Shoemaker Protocol?

Durand 29:23

Oh, the Shoemaker protocol is a series of tests and a specific treatment plan for Chronic Inflammatory Response Syndrome, it’s a mold thing, Lyme Disease and also MCS and my other conditions I think would be way better if I could be treated. The doctor I was being referred to took more than mold into the equation. He would have been able to find the root cause. I could not afford to see him. The initial portion of seeing him would have cost between $10-20,000. There is no way I can afford that. Yeah. Dr. Ritchie Shoemaker is the guy who created this protocol. So anyways, my psychiatrist tried to get me to see the doctor who practiced the Shoemaker Protocol in another province and Manitoba Health said no, and that they wanted more information to understand the protocol. I provided them with the information and they kept wanting more, so I had to have a hearing. I attended a hearing. I attended by phone, I had an advocate and I lost the hearing but they said if I found a different doctor it would be seamless. They wouldn’t or couldn’t agree with what the psychiatrist asked. They wouldn't do the testing because they only wanted one test, not a series of tests, and they said they didn’t understand the tests that were required to diagnose, nor did they understand the treatment plan. So anyways, I lost that hearing. My psychiatrist then sent me to a different doctor in another province outside of Manitoba, an environmental doctor which is not necessarily the same type of doctor that I was first advised to see. In that process, I drove to another province to see this doctor in 2017 and came back to Manitoba. I was going back and forth from Manitoba to this province and living in my van. I was fortunate to find others with the condition where I could stay while there as well, off and on. The last time I was in said province where my environmental doctor is located, before I lost my disability from Manitoba, which I have had since around 2000, I was apparently in that province too long waiting for Manitoba Health to okay my next set of appointments. I could not afford $800 to go back and forth for gas. Also, my van was in the shop getting fixed and I was in-between appointments. I lost my disability in 2018 and since then, I've been searching for a general practitioner who would take me as a patient and complete disability forms.

Kim

I have a question about something you had kind of mentioned a few minutes ago. You said the psychiatrist or psychologist, he wore something scented one day, was that on purpose to try to trigger you or just a coincidence?

Durand

I don't know. I don't know because he was genuine in finding what it was. He may have wanted to know how I was affected or maybe it was a coincidence. I don’t know. Once we found the culprit, I said, let's take a look, where's the ingredients, is fragrance on listed on the package? Is the word fragrance in this? [laughs] We looked to see the ingredients. He apologized. He was very considerate. In our visits he realized I am truly suffering from the effects of mold in my living quarters and MCS. He sent me for lab tests. The lab would come back to him and say I could not have the tests performed. So anyways, I paid for the HLA [Human leukocyte antigen] test and found out that I'm one of the people who has a gene for mold exposure. I searched out a lab who would draw my blood and I sent it out to the location which performed this lab test. I had all of the symptoms and diagnosed medical conditions mentioned in the research for CIRS. I knew I had CIRS. My psychiatrist did everything he could to get me tested and he lost every single battle, so to speak. He did what he could, including writing a letter Social Assistance Disability to let me go camp in the desert and asking for an organic diet and more. I was advised I would have been cut off from disability. When I went to the other province to see the environmental doctor my psychiatrist referred me to, the part of the treatment advised from this doctor was to live in the desert in my van for the winter as well. Now here I am in the desert during COVID. I can't get back to the Canada because I can't afford it at the moment and my van needs so much work. As well I cannot meet COVID quarantine plans to cross the border as well because of my van.

Kim

Sorry there seems to be some sort of wind or something right now. Sorry.

Durand

Okay, sorry. Is this any better?

Kim

Yeah, I can hear you.

Durand

Okay, sorry.

Kim

Oh, no, no problem. Sorry. Please continue.

Durand 33:08

I forgot what I was saying, we can keep going. I’ll remember eventually.

Kim 33:13

Okay. So sounds like we kind of went over an overview of how you came to be diagnosed with MCS or getting this kind of doctor's approval and how they weren't really advocating for you, except for your psychiatrist. I was wondering if we could talk a little bit more about your activism and advocacy just since it seems to be such a such a huge part of your life?

Durand 33:38

Oh, it's all I do. [Laughs] Sure, what would you like to know?

Kim

Can you talk about how you first got started with it?

Durand 33:48

Okay, well, there's many reasons. I kept on facing all the barriers. My family and friends and organizations were having a hard time understanding what I am going through except my mom. Okay, so to go back a bit, in about 2013, while still facing all the barriers, I decided to volunteer for an online news hub and learn how to write articles as a citizen journalist—I had no clue how to do this. I went into the meeting, and having a hard time not understanding things like maybe I could have. Then I said, I really want to write about multiple chemicals sensitivities. Well the head newspaper guy from the local biggest paper that was there, basically was like, what it seemed to me as not so understanding, blah, blah, blah, he was saying that I was too close to the issue and I had to prove it, prove it, prove it. So I didn't write an article on MCS until like, over two years later because I was too busy trying to research and trying to prove it. I began writing other articles to learn how to write and work myself up to write that article. There was an opportunity to write an article for a disability article in a local magazine. I wrote about my situation and how photography has helped me. My editor for the online news hub shared the article with permission from the original publication. My editor said I've done enough to try to prove MCS, and I continued to write the MCS article. So I finally wrote the article, but in between that time I wrote articles upon articles of different things that I saw in the community, nothing related to MCS or mold, while just trying to figure out how to write something related to MCS and or mold. In the end, I wrote fifty plus articles as a volunteer citizen journalist in total. My brain hurt, I was living in mold, I couldn't think and stayed up all night trying to write an article, trying to understand what the person said, who I interviewed—I couldn't even function on many levels. I did my best to communicate with my editor. I know I messed up on some things. I was diagnosed with a certain kind of amnesia at that point and was also told I was going to die for another health issue. And before that, I was bedridden. I couldn't get homecare. I couldn't get anything. So we can get back to the bedridden part to how I came out of all that. And then, and I can't remember what year, maybe 2016, I can't remember. I was in an art show called Canary in the Coal Mine. And maybe right before that, I think it was for—I remember there was an election, can't remember, the Green Party or whatever. So then I started writing about MCS. Then, I started finding more people like me. And then when I found out that people were taking their lives, people in the mold groups and MCS groups I felt something within me that I really want to do something to help. And it's like holy crap like, this can't be happening. They are losing the same things as me: their family, friends, their job, disability, medical supports, self-identity—like everything and no support of any kind. For some reason, I got stronger. I began to talk on the radio. I never would have gone on the radio. I remember in university, I had top marks in one class and the professor brought me aside into his office and mentioned that ten percent of my marks count for talking in class. Well, I guess my jokes didn't count as talking in class. So I had to start talking in class about the subject on hand, but I was so intimidated, I would cry. I think I did cry a few times because I felt what I said didn't matter. So anyway, back to 2016, I started talking on the radio. I began talking on the radio, because now I felt I had a purpose. There's all these people who need help and who have no voice. I have nothing to lose. I have everything to gain by trying to help. If I can get a resolution going or get something going, it may not help me now, but it's certainly keeping me going and letting me have a purpose and maybe it will help the people now and people in the future. I just want to be able to help people now. Now I have a purpose. My heart just breaks every time I hear about the struggles of my Facebook friends and friends I have met with MCS, especially when someone takes their life. I was always sick and felt I had no voice. But now I know if I just leave my environment, I am still sick but I can function somewhat better. Back to 2016, after I lost all I owned due to mold, I was at an old friend’s place, on my computer, and I saw all these people struggling and some not wanting to live anymore and how horrible this whole situation was, like, holy crap. Most every one of these struggles that these people are saying is similar to what is happening or has happened in my life. The majority of people—family, friends, people in organizations, everybody—couldn’t believe what was happening in my life. They would say that I was exaggerating or making up the situation. And I'm like, no, this shouldn’t be happening to all of these people. This is happening to a lot of people. So I began asking their permission and collecting quotes of their struggles to share in my art projection I later named, “WHO says we need fresh air?!” And then I collected the quotes from people from around the world and began projecting them onto buildings as an artist even before the project was fully complete. The situation was so dire, I felt I could make some kind of difference for those who were truly suffering. So in I think 2017, I shared the quotes in “WHO says we need fresh air?!” at the Winnipeg Centennial Concert hall in Winnipeg, Manitoba on May 12, 2017 on MCS Awareness Day, outside the building during a ballet or maybe an opera, on a large TV screen. The Winnipeg Centennial Concert Hall has a share-the-air policy where they are trying to have clients and staff be scent-free. So I thought that was a good choice to share “WHO says we need fresh air?!”

at that venue. Then later on that month, the Sioux Falls Canaries versus the Winnipeg Goldeyes baseball game allowed me to share a couple quotes up on the screen during the game. I thought it was fitting. And then I did something else that month during what I called a tribute to mothers on Mother's Day. I can't remember how I angled it. I wanted the mothers to see the quotes and help protect their kids. It was more than that. I just can't remember. It was so long ago and so much has happened since then. But you get the gist, like I tried to fit it into every way so that people could see what was happening in Manitoba, Canada and the world, and begin to understand in hopes they can also make some changes in their life. What is happening with those living with MCS could also be happening to the viewer, their children, family, friends or coworkers. "WHO says we need fresh air?!" could help people understand what is happening around them. Like, I got sidetracked there. Anyways so that was the "WHO says we need fresh air?!" project.

And then end of 2016, I found out my mom was on a resolution committee. I mentioned to her that I don't know what a resolution committee was. Mom was on the resolution committee for the Catholic Women's League, and I ask her, What is that? She said she writes proposals and things to help make a change. I go, "What, so can you do something for MCS?" And so she had to run it by the committee and everything as it's a hard sell. They said yes and I provided my mom with all the research. I included mold exposure in it and electromagnetic hypersensitivity [EHS] as well as MCS. It took us a while, and we got it all written up and my dad's so against my mom talking to me about all of this. [Sentence has been embargoed]. And mom and I just kept working really hard, back and forth with emails. That was all we could do. Mom saw the situation I was in with no place to live where I could have a better quality of life. And so the resolution was created. I feel really bad—the day it was completed, my mom's hip broke so while she was outside the church. My mom couldn't defend the resolution because of this, as she was transported by plane to Winnipeg. Nobody in the Catholic Women's League [CWL] really understood it or could defend it like my mom could have. They did their best. Eventually the resolution passed all the way up to the national level which was the last level before the Prime Minister of Canada would have seen it. The CWL National level said there was enough awareness so they would not pass the resolution. I was asking to have basic needs met, including housing and shelter or food, medical, a medical diagnoses code, and so much more for those living with environmental sensitivities and mold exposure. Anyways, it didn't pass. They said there was enough awareness out there. I was actually so upset about this that it gave me even more whatever to keep on going. So CWL is now saying that there is enough awareness. I had to keep on going because there's got to be some way for people to start getting help, this is ridiculous. I would not be homeless or facing all of these barriers if there was enough awareness. So anyways, during that time, I had a meeting with one of the local politicians with the Green Party of Manitoba. I arranged to share "WHO says we need fresh air?!" and the resolution with them later on that year while I was in the other province seeking medical care. I presented the resolution and "WHO says we need fresh air?!" via internet. At the time I was in the other province seeing the doctor, and here I am talking to the Manitoba people on MCS Awareness Day trying to get help for them in Manitoba. Manitoba is the province I had to leave, I'm really advocating for the people in Manitoba at this point. The response at the meeting was very positive—they were going to consider the resolution at their next meeting where they pass or consider resolutions. Well, the federal election was happening and that took up all their time. They did not even look at it from what I am aware of. They did not answer any further emails or phone calls. I first met the Leader of the Green Party in my van, and later a person on the resolution committee outside the van. Since then, I've been approaching people, writing emails to organizations, you name it, to have the resolution passed. End Homelessness Winnipeg invited me to attend a meeting because they were considering building housing to include people with MCS. And while I know that it's way too much of a challenge for most places to even contemplate building places for people like that, they included me, which was great. So I, of course, shared the resolution with them as well, but they didn’t have the ability to look at it. They had key people there who could help make a change at the meeting. I haven't heard anything of the outcome of that meeting in relation to MCS housing. In my last contact with them they had no answer. So after all the hard work, here I am in the states now fighting for Canada. I recently proposed the resolution to the Green Party of another province, and now they have it under consideration for their province, though it needs to be written up differently to meet their requirements. I asked another lady from that province who is helping me with the resolution to meet their criteria. Last month I spent all of May working on the art show “Air on the Side of Caution” during the awareness month, and now I am having challenges with understanding things due to my EHS symptoms.

I’m also working on a petition. I mentioned how hard it was working to pass the resolution, and how I want to do a petition but I don’t understand the rules. So Jenel Shaw offered to help me. And then, hopefully this week, hopefully, the Member of Parliament, who I contacted and shared my art show with, will back the petition to go to the House of Commons in Canada. I am hoping I can meet the Prime Minister of Canada when the petition has the required number signatures, and share “WHO says we need fresh air?!” and ask for help for those in Canada. While I was in Arizona, I video recorded a couple of people with MCS and added it to the videos I took in Canada. I have a friend who has MCS as well, across the other eastern coast of the state. He edits a lot of my stuff because I just can't be on the computer that long. Around January 2020 I sent him all my footage and entered this contest for the World Health Organization [WHO] called “Health for All,” around the end of January or February of this year. I was asking for awareness and acknowledgement by the WHO for environmental sensitivities. The video did not win, though I can submit it again the next time around. If it won, it would’ve shown on May 12—but whether or not I won, I was going to show it on May 12 anyway since that's MCS Awareness Day. So while the WHO was sharing their winners on May 12, I shared my film through Film Freeway. I also shared it during my “Air on the Side of Caution” art show. My friend and editor and I worked hard and put the quotes from “WHO says we need fresh air?!” into categories and shared it during the show as well. I invited the Prime Minister and as many politicians I could.

I also shared ‘WHO says we need fresh air?!’ during a solo art show earlier this year which I named “Endangered Humans - PJ Days,” in Jasper National Park during an autoimmune event. I chose Jasper because they have pristine air. The “WHO says we need fresh air?!” was shown at other places as well, notably, my hometown. I did receive a comment that I was lucky I didn’t get my life threatened. Since it was a pulp mill town, I projected the quotes onto the local newspaper building with permission.

In either 2018 or 2019 I projected “WHO says we need fresh air?!” at Manitou Beach at the local art gallery during an event called “WOW!Manitou.” I chose this place for its healing waters. We had discussions about it from people at the event the following day. Naomi Hunter was there and running for the Green Party in Saskatchewan; she really liked “WHO says we need fresh air?!” and tweeted someday she would like to work with me.

Kim

Wow. That is a very incredible list of advocacy and activism. [Laughter] Well that was a lot—no, that was great.

Durand 50:06

The short answer or the long answer. But there's been so much. I go from place to place trying to get an interview with the newspaper and have a showing of “WHO says we need fresh air?!” A lot of them are just, they don’t care. But I’m going to keep on trying and doing.

Kim 50:25

Can I just ask, I mean this is obviously, this is a lot of extensive work and just kind of given what you've already said about yourself, I can definitely see you—you talked about in childhood and university, really pushing through, being like the go-getter, involved with everything. So I can definitely see this trend with the way you approach things, like very proactive. But then you also said that you were kind of shy in college so I think it's a very interesting mix of being someone who doesn't really like talking in public with someone who's like a real go-getter. Because I think advocacy really, you're mixing a lot of different methods, you're doing a lot of like letter writing, and a lot of speaking with people, so it sounds like, did you have to overcome any sort of shyness or anything? Or like, did you try to do things where you can say, like, a little bit more behind the scenes and not have to talk in front of too many people?

Durand 51:35

I actually kind of like being in front of—and behind—the scenes now. [Laughs] It's so weird. So I think, I’m behind the scenes on a few things, but I think back from when I was in university, I thought, well, everybody's smarter than me. Plus, if I'm reacting, it messes with my brain and so then I feel less adequate than others and cannot express myself like I could. And now, I don't care. I mean, I do, but it's like I've faced every single one of the discriminations and barriers at this point. In settings in university if I was to share knowledge I was very uncomfortable if it was something I had to talk extensively about. If a short answer was required in class I would spout it out. In social settings it all depended on the triggers. I had no idea what was happening to my body. The reactions created havoc in my body and no one believed me. Some people think I am an extrovert, some think I am an introvert. I am on the fence on that one. Kind of both depending on the people and situation. I like the large crowds for my art and small for any gathering and personal.

Kim 52:21

Oh it does. It sounds like you've been in some ways, like empowered.

Durand 52:25

Yeah, so I should thank all those people for just being jerks. [Laughter] But anyway, maybe I'll have a book and call it, 'Thank you to those who did not understand'—not sure it'll be something positive for your kids I am sure. I'm just joking. I have no idea. But it's like many people are very mean, and there's all these people, including myself, facing all the barriers that everybody's going through, it just made me stronger. I can't bear to see what's happening to everyone. But in the beginning, I wasn't so strong. I would get mad, I'd be angry with Social Assistance Disability because they couldn't help me. Then when I asked social assistance one time, I said, so who makes the rules? They say, Not us. I say, Oh, well then who? Then that was it, a point where a light lit up over my head. It's like okay, I can't get upset with the workers. It's not their fault they cannot help. I already know they can't do anything because they will lose their jobs. It still pisses me off to no end that no one can go to bat for us without penalty. It is just another barrier I added to my checklist of barriers. Before it used to make me so mad and so depressed and now it's like, okay I understand. It sucks. But I know I have to reach the policy-type people somehow to help make a change. So the more I could just keep saying, okay, yes, you guys can't help me, the larger the list of barriers became. Many thought I was making this up. Right here it is, it's a checklist of things we need for accommodation and what I went through. This does happen to a majority of people with MCS, mold exposure, and Lyme. So the outcome is still the same; housing and medical and so much more they need and they aren't getting their basic needs met. I have relatives that were going to help me with housing at one point. I was out in the middle of nowhere and I needed a vehicle to go find housing. I was basically told that I needed a place to live, not a vehicle. In the middle of nowhere and not able to take a bus I really did need a vehicle. I could not do it their way no matter how hard I tried. I did look at some places. Each place I could not make work and did not have the means to pay. So anyways, that didn't end up very well. I was yelled at how bad of a person I was. That week just prior to this particular conversation I had just lost my portable housing funds and literally hearing how basically it was all my fault was really hard to hear. [Sentence has been embargoed]. I'm thinking if they're offering but yelling at me and telling me I'm such a bad kid in the family and how much trouble I've been I don't think I really want to take anything and then get yelled at if I had to move again and it didn't work. Since then my relative has not returned my phone calls. It feels like I have no family for the most part. I just needed a van to revamp to live in and go to the desert which was the prescription at that time. Apparently it wasn't reasonable to my relatives.

Kim

Yeah, definitely sounds like—

Durand

—so I can't

Kim

You reached a point where it's just like you need to say what you need. You've had so many obstacles already, you have nothing to lose by just saying what you need and advocating for yourself.

Durand

Yeah, yeah, basically, because before I used to just do what people were asking. I wasn’t believed, so I would do it their way. I guess I'll just try it, I am thinking. I would get sick. And then now it's like, I still do that a little bit, but not to the same extent however. Now a lot of times it's like, forget it. Some people are so adamant about making comments of how they think it's in my head. And finally I say, well, so when someone hits you in the head with a two by four, does that hurt? Yeah. Well, if someone keeps hitting you in the head with that same two by four, does that keep hurting? Yeah. Well, that's like fragrance with me. Oh, I forgot a big one. Manitoba Health. Okay. I wrote a letter to the Health Minister of Manitoba, and I wrote a letter to the Prime Minister of Canada trying to get help for people with MCS. The Prime Minister’s office or someone in the political realm—I can’t remember—someone in their office had someone talk with me on the phone. I was in a really dangerous situation where I ended up getting my life threatened in this one situation. During the conversation I asked for her email address, I couldn't talk about the dangerous situation while the person was right there, right? I wanted to email them so I had some contact. This person wouldn't give me her email and finally did but would not look at her email. She really wasn’t getting it so she really wouldn't give me help. And then I asked, What do you do to help the people with MCS in Canada? She took offense to that. She said, “I'm the immigration officer, I take offense to that.” I figured at that point asking for help was going to be impossible, so I figured I am just going to shut up now. It's like, yeah, okay, I'm not going to get anywhere with this. So I didn't, and I was so upset. And then eventually, after several months I received an email from someone in Manitoba Health who was referred from the Health Minister’s office from the letter I had written several months earlier. This person was requesting to have a meeting. It was a meeting to help make a change and the lives of those living with ES/MCS for the better, or so I thought. I attended the first meeting with the top person who's going to help with policymaking for MCS on the phone, I mean, I thought. I brought in one organization and a non-MCS person who used to be a policy maker in another type of business to help make this happen. We had at least another three more meetings or so, I can't remember. We were discussing a lot of things and I was advised to take mold off the table. Anything to do with mold. I had to take mold off the table.

Kim

That’s a big chunk of your work. Wow.

Durand 58:47

I was, I’m like thinking to myself, Oh shit really? I didn’t say that word but tempted. So anyways, and then the one person from the organization said, just do what they say because we’ve gotten this far. And the person from the organization who I bring into meetings can’t understand how I am getting these meetings and she’s not. I have no idea how I'm getting the meetings either. I just ask and share some of my story and the story of those in their location, Canada, and around the world. But anyways, so we have had at least three to four meetings in total. And then the Manitoba Health lady started to be unreachable. I’m guessing the Health Minister or someone else cut off the meetings. They must have realized it's a big thing we are attempting to do. They're not going to make any money off of us. I haven't been able to get any more meetings. And I really was hoping. The lady had a kid that has a lot of allergies. I am sure she probably would have went further if she could have. Some top person, higher than her I think seems to have shut the meetings down. I know so. I am just hazarding a guess. In a phone call she advised me to save myself. So anyways, this Christmas would have been one or two years since I had those meetings. Maybe, I don't know, but it was a long time, and then I phoned her up again. Of course, she didn't recognize my phone number but oh you can hear her voice like, Oh crap, as she hears my voice on the other end. So anyways, well I can't remember everything she said but in the end it was basically that that she would bring up MCS at the next meeting coming up to do with accommodating people. This was also said by her the year prior as well.

Kim

It’s still an accomplishment to have gotten that far in and of itself. So that's pretty incredible.

Durand

Thank you. I noticed that when I have an art show that I'll receive an email or an unusual letter from somewhere. For example, I had an art show and I received this government type of card in the mail at a previous address. Like why in the heck would they be sending this to me for? Really? In all my fifty-plus years I have never received a card like that from said organization without requesting it. I am thinking it is just to let me know they are watching me. I'm not sure. I could be totally wrong. Why would I receive it? Especially since I am not there anymore. I mention this part because I receive messages from people mentioning for me to be careful. So I am cautious. Other things have happened right after an art show where I receive something from the government I never requested that normally may not have been sent out.

I'm actually going to contact a politician today and see if they can contact someone up there in Canada, so I can get some money so I can pay for my van to get fixed and make it back to Canada. I'm frustrated. Here I am, I can't qualify for any of the COVID stuff because I didn't lose my job during COVID. And I can't get my Disability—I have to cross the border and give them an address but there's no housing for me, and then give them whatever paperwork they want. And if it doesn't work out, that means I went all the way up there for nothing. And not have gotten my Disability.

Kim

Oh sorry, just speaking of COVID, we're actually also wondering if COVID had affected your experience with MCS in any way.

Durand

Oh how I love this question [laughs]. Okay, well, life is normal as usual. Wait, am I not under quarantine all the time? It's double quarantine for me I guess. So the part of my life that's affected is that a lot of times I would stand outside a store and ask someone to go in for me and give them some money to go in and get what it is I need, or I ask the person in the store to meet me outside. I can't do that now with quarantine. So I'm going into the stores now and getting sicker. Oh, COVID. Yeah, okay, so I had to start going into the stores but then of course I'm going in and I'm coughing because I'm reacting to the smell of scents and lord knows what else that permeates through my mask. So I'm like saying out loud to customers who are looking at me, "It's not COVID, it's the cleaning chemicals that are making me cough because I'm reacting to chemicals." I don't like going into the stores because I buy everything I don't even need because I can't think straight. And I totally embarrass myself in the store. And so I don't like going in because I make an ass out of myself literally. And so yeah, so really it's not any different because life is the same but the different factor is I can't ask anybody outside a store for help at all.

Kim 1:05:22

Is it because of social distancing?

Durand 1:05:26

So I can't give them money to go into a store for me now, I can't. So I don't even want to go shopping and then the food now tastes—oh, here's another one. The extra cleaning chemicals they spray I can taste in the food. Yeah, let's keep adding chemicals on our organic food. Because they're spraying all that stuff in the store. Oh, wait. Here's another thing. One reason that besides finance, another reason I can't go back to Canada is because my van does not meet quarantine rules. So I have to have the proper facilities inside my van if I want to camp in a campground. I don't. If I have a shovel and ground I can use for a bathroom I am good. Someone tells me [unclear]. But yeah, my van is not self-contained to the so-called normal standards. It was in the beginning when I bought it because it's a RoadTrek camper van. It's always broken down. So it's a really old '91

RoadTrek. When I bought it, it had a propane stove top, it had a toilet, it had a sink. It has nothing like that now because I gutted everything due to serious adverse reactions to the scent and the wood and propane in the van. Everything's gone. And I know there's mold coming through the vents and I've taped them off. I really just need a different van. I forgot what I was going to say but COVID, life is pretty much similar, like people are bitching and complaining, they can't have their haircuts. We can't do this normally, we can't do that. That’s our normal life. My sister sent me a picture of her wearing a mask. So, now it's a fad, I don't feel so self-conscious wearing a mask—if I can tolerate it—in the store. But in the places that I've been going in lately, people are still gawking at me wearing a mask, because a lot of them aren't wearing a mask. Yeah, so some of these places that I was in recently, they’re like giving people hugs, they're like shaking hands or whatever. I'm like, Oh my! Yeah. And then the one place where I did stay at, so I went all the way from Arizona to go to a town in Utah, because I did a lot of bartering this winter, the person kept wanting a hug and touching me. So, since I have no money, I went all the way up there from Arizona because I promised them I would help them with their gardens in exchange for me getting some organic food and help with the van.

Kim

Oh sorry, there’s some interference right now. I think I can hear you now.

Durand 1:08:53

Okay, so I went—there’s another bicycle going by, I'll wait until that one goes by. Okay can you hear me now?

Kim

Yes.

Durand 1:09:20

Okay. Oh yeah okay so I’ve done a lot of bartering. Actually when I went to that doctor in the other province, I stayed at a place. First place I stayed at the lady had MCS. Second place I stayed at, they had mold and they have a whole family with sensitivities. That household has three generations of people with MCS and I was trying to get their story but I couldn't. But anyways, when I was there, I did a lot of housework and a lot of things like babysitting, whatever, just to pay my portion. Then in the end the lady liked me so much she got a grant so she could hire me for three hours a week. I got paid but I still did a lot because I was staying—in the end, stayed outside on the street outside of their house. So I just helped them with whatever. But right before I left, the scent and mold in that household were getting to me, she could handle a certain shampoo. I was so sick. They wanted me to stay there so I could try and get my Disability but I was too sick and it was getting too cold in my van. I really miss them. They are an amazing family. My doctor kept strongly advising me to go to Arizona. So the last week or so I was there, I was literally crawling on the floor when I was cleaning the floor. I was so sick and the mold in there and shampoo, I couldn't do it. I couldn’t stay. Just before that, I was staying in an older gentleman’s house where I thought would be safe. But anyways, his house had mold, and I kept saying, your house has mold. His previous wife had died from dementia which she was diagnosed with shortly after moving in that house. And I was losing my memory in there. And I said she died because there’s mold in here. He's like, No, there isn’t any mold. I persuaded him to have his place tested for mold. He had higher amounts of mold in there than it was even allowed. He had some work done to remove the mold and put in an air purifier system. I was still so sick in there. And so anyways, I left that environment after I had kidney failure in there. I would not go to the emergency room because I've had enough surgeries. I decided to leave the environment as I knew that’s what it was. And a week later my kidney counts as I call it were back to normal. So that's how the mold in there and the fragrance affected my kidneys and so much more. Even the electrical and smart meter affected me so much. I forgot where I was going with that—oh yeah the bartering thing. Okay, so then when I went to the states, in Utah on the way to Arizona, I stayed on the property, helped them with the gardens while I stayed there. Then I went to Snowflake, Arizona, and shot some videos and collected stories of some of the people of Snowflake living with MCS. Then I went to another area in Arizona. One of my new friends was so kind to show me the ropes of camping in Arizona on BLM [Bureau of Land Management] land. I met a family in this place in Arizona who had mold exposure, Lyme, MCS. A family member came there who had Lyme and I was giving her coffee enemas and whatever was on the protocol for her care. I was doing a lot of other things to earn my keep, such as babysitting and homeschooling, in which I gained new skills and insight. And then when I came back to where I am at now in Utah, I promised I would help on their farm doing gardening and other yard work in exchange for organic food and work on my van. The lady was basically a slave driver and the husband kept trying to pick me up the whole time. Hugging and touching me during COVID. And so I'm out of there. In this town the first question people ask is, “What are you running from?” I’m like, what? So apparently this is really the wild, wild west. Kind of scary. I felt like I was in an old western movie or something.

Kim 1:14:36

Yeah. I just have a few more questions to kind of wrap up the interview. One question that we're asking everyone is, do you think that gender has affected your experience with MCS in any way?

Durand

Yeah, the doctors just want to ignore the whole situation and medical condition. Yeah, because it seems like they take males more seriously a lot of times, but maybe not with MCS. The doctors have been very condescending. To me it just feels like they think, “She's just like complaining about a little symptom,” whatever. It's just like, “There's nothing wrong.” They always want to send me to a psychiatrist. Or on the other hand, they send me to every specialist there is and find out there's nothing wrong or a lot wrong when I am in a certain environment. The same results on tests only show up on certain tests for their particular specialty, depending what environments I’m in. Coming back to family members and friends, I still think gender is a big issue. Even when I'm requesting someone for help from an organization, it still felt like gender was an issue. It was awful, but also they're not trained in multiple chemical sensitivities. So it could be both gender and lack of awareness playing a factor in that and all cases.

Kim 1:16:03

Yeah. And how about race? Do you think race affected the way that you experienced MCS in any way?

Durand

If I have access to what I have—which isn’t much to begin with—someone who is even more disadvantaged than I am would have even more of a harder time.

Kim

That's actually all the questions I have. Is there anything that you would like to add or any questions for me?

Durand

I wish I had better internet because I wrote something called ‘My Adequate Housing Process’ since like the year 2000. And I also have something else called ‘My Book of Barriers.’ It’s on my computer somewhere but, what I really want is, I want a checkbox on any Disability and government form for people with ES/MCS, because, for example say, I need a gluten-free diet or organic diet. I'm not celiac, and I'm not allergic. Therefore I don’t qualify for the special funds that I'm allowed for that diet. So that's another reason. That was one of my other barriers. So that's another reason I want that checkbox is so that we can start getting things like that including assistive devices. An example of an assistive device to me could be an organic bed, not the existing kind for the people in the wheelchairs. We need an organic bed, we need meters to measure Wi Fi and other things in the environment, we need the proper testing of an environment before we move into a house with mold. That's an assistive device.

Since the interview[1], my van broke down in the desert, so I went back to Canada. The first attempt I was turned away as I did not have a good enough quarantine plan. I ended up finding someone in another province who would let me stay on their land in Saskatchewan and quarantine. I am still working with Disability to see if I can receive it. I am told I cannot receive provincial Disability or be approved—if I can even provide them with the proper paperwork—until I cross the border. I feel this is cruel and unusual punishment, although perhaps this is the norm for those of us with MCS. I did not meet the requirements on any other forms of payments the government was giving out to help those during COVID. I also had applied for an exemption so that they would let me stay

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[1] The following has been added after the interview, at the narrator’s request.

in the middle of nowhere for the fourteen days. I have not heard back from them almost a month later. For COVID they wanted a person around during quarantine. I had it all planned out with food and everything. I had a few different plans and they said no to all of them. They could not accommodate me. I was advised from Customs that they cannot turn a citizen away. A Public Health nurse advised I go back to the US for a few days to come up with a more solid quarantine plan. I even asked if I could stay outside of their designated hotel and they said no.

Also, since the interview I had help from Jenel Shaw in contacting a government Member of Parliament of the Green Party of Canada, Paul Manly, to have a petition created which he will present to the House of Commons. Within the week there are over 250 people who signed. Over halfway there! I created a video as well for this petition.

I also forgot to mention that there was a review for The Accessibility for Manitobans Act. I secured a meeting with them and invited an organization to join in the phone meeting. In the end when I received the link to the review at my request, I found that environmental sensitivities was not mentioned. I did notice, however, that Ontario mentioned it. I sent off the information to the person who reviewed The Accessibility for Manitobans Act. This was either in 2018 or 2019.

Also, at one point I received an email from a place that was creating a docuseries for Netflix. I was interviewed but didn't make the cut in the end. My father decided not to participate which ended the conversation between the producer for this series. They wanted to show the conflict. In the end the proposal was that they would take into account my advocacy as I was to go across Canada and create awareness while I could not access housing. My part did not make the cut; in a way I am happy about that. The controversy surrounding the docuseries is not very good. The people they interviewed apparently were not represented properly and apparently there is a lot of litigation happening because of the misrepresentation.

At another point a few years ago, a local TV station interviewed me for the third time. The person who interviewed me about a piece of art was wearing something scented. I had a major challenge during this interview to keep my concentration. It was an interview outside as I needed as much concentration as I could jumble up. With the exposures I ended going into the local sports store after the interview to replace some of the belongings I had lost due to mold. Apparently I was talking about the interview with someone I recognized in the store. I was talking really loud. When exposed I talk louder and my senses are messed up. In the store I was dropping things. Later on I found out that the interview was never shown on TV. The person who arranged the interview asked if I went into the building. I said no—I totally forgot about the sports store. I was only thinking about the location of the interview. Later on a comment was made about something someone said one day. I had a flashback about who was in that store. It was the person working from the opposing TV station. The only thing I can think of is that this person sent a video or something to the manager of the other TV station. Since then I have not been able to get another interview. I have asked to speak to the person but they have been unreachable. I am thinking the other person from the other TV station sent a video or something. I remember in the store the person I was talking to kept saying out of the side of his mouth to be quieter as someone is watching. I had no idea. I remember being upstairs in that store and saw two people who are from the other TV station. It took me months or maybe over a year to figure it out. Actually the video they would have of me would actually be good representation of what actually happens to me during an exposure at that point in time.

Thank you so much. Thank you for everything you're doing.

Kim

Thank you.