

## Oral History with Beauty Belle

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Interview of Beauty Belle

SESSION 1 (4/2/2020)

[00:00:00]

KIM: This is Kelsey Kim for the Center for the Study of Women and I'm speaking with (Beauty Belle). All right, so if I can just begin. Can I ask when and where were you born?

[00:00:15]

BELLE: I was born in Elmhurst, Illinois. Do you just want the year or the date?

KIM: Anything you're comfortable with. You can say the year if you want.

BELLE: May 1963.

KIM: Okay.

BELLE: So I'm fifty-six.

KIM: You said Illinois, right?

BELLE: Yes.

KIM: So, what was it like?

BELLE: I'm from Chicago.

KIM: Chicago? Oh, okay.

BELLE: I'm from Chicago.

KIM: Okay, what was it like growing up there?

BELLE: It's cold. But I live in the South now.

KIM: That's nice. Yes, I imagine it's cold over there. Did you have any siblings that you lived with growing up?

BELLE: I have two brothers and a sister.

KIM: Okay. What did your parents do?

BELLE: My dad was self-employed and my mom worked at the department store.

KIM: Department store? Okay.

BELLE: They both had health issues, but not this.

KIM: Okay, do you mind if I ask what their health issues were?

BELLE: Sure. My dad had congenital heart—congestive heart? Yes, he had a really bad heart. He had congestive heart disease. My mom had rheumatoid arthritis her whole life, since I was born. So, since 1962, until she passed away, and then she had ovarian cancer.

KIM: I'm sorry to hear that.

[00:01:54]

BELLE: They were both very sick.

KIM: But no one in your family—?

BELLE: My dad lived a long time.

KIM: Okay.

BELLE: —congestive heart failure, congestive heart disease. When I was growing up, nobody in my family had this issue. Everybody has it now, but nobody had it. We're finding out that a lot of my family has it now because I started talking about it, so— but growing up, it never bothered me. I didn't really have allergies—it didn't start until I moved to (the South).

KIM: That's interesting. Now you're saying that you recognize that some of your relatives have developed it recently?

BELLE: Yes, my niece—my sister sort of has this issue now, where she didn't either, before. A couple of my nieces have the same issue. They're back in—my nieces live in Chicago and my sister lives in Tennessee. Just since I found out that I've been having it and talking to family, they've determined that that's what's bothering them. So, I've helped them go, “Oh, that's what's making me sick.”

KIM: That's fascinating. So, you're the first person in the family to realize this—

BELLE: Yes.

KIM: —and then they realized “Oh, I have this as well.”

BELLE: Correct.

[00:03:19]

KIM: At what point was this happening? Was this is just a few years ago?

BELLE: Let's see. I moved to (the South) in '05 and it started around—brief, I started noticing something in '06, '07, that scented products, like perfumes and stuff, were bothering me. Then in 2013, 2014, it got really bad—

KIM: Oh, I see.

BELLE: —because of lovely air fresheners.

KIM: Yes. The glade plugins—everyone hates those.

BELLE: No, my workplace started putting air fresheners in restrooms. That's what triggered it to be worse. I work for a Fortune 500 company, so yes. Or, I used to work for the Fortune 500.

KIM: If I can just back up a little bit—

BELLE: No worries.

KIM: This is super interesting, and we'll definitely get to that.

BELLE: If we get off topic, make sure you follow what you have to follow.

KIM: Thank you. So, what was it—I'm sorry. Do you remember growing up in your childhood home—do you remember any particular scents or do you associate your home with any fragrances?

BELLE: No.

[00:04:46]

KIM: Do you remember any cleaning products used at home?

BELLE: My mom used Lysol, Spic and Span. Those didn't bother me then, when I was little. Our house was pretty old.

KIM: Oh, how old is it?

BELLE: It was built in—let's see, the 50s?

KIM: Okay, was there a mold issue?

BELLE: Probably. Probably.

KIM: But it didn't bother—?

BELLE: We never saw it, but probably, because it was a very old house.

[00:05:28]

KIM: Can you describe your neighborhood to me?

BELLE: Lived in the suburbs. We lived—there wasn't a lot of houses on our street. We had a pretty big yard, like, little less than a half-acre.

KIM: Pretty big.

BELLE: Yes, it was pretty big. Had to cut it. The grass really didn't bother me either. Occasionally I'd have seasonal allergies but not a lot. A little bit when I got older. I'd start taking allergy—no, actually I never did. I didn't take that much stuff back in Chicago. It was when I moved here. Nice little move out because it's nice and warm, so.

KIM: Did you go to elementary school through high school in the same neighborhood?

BELLE: Yes, I lived in the same house until I was forty.

KIM: Okay. Very nice.

BELLE: Until we moved down here. Everybody teases me because I lived in the same house, because I bought my family home, after I got married.

KIM: That's nice.

BELLE: So, I lived in the same house my whole life.

KIM: Did you enjoy school growing up?

BELLE: It was okay. I wasn't a great student, just did it to get by. Didn't go to college, just went to high school. I didn't go to college. I do more—I'm better with on-the-job. I learn better doing instead of being in school, so I really didn't go to college.

KIM: Okay, were your schools not really receptive to different types of learning?

BELLE: Not back then. Not back then.

KIM: Maybe not so much like they are now.

BELLE: Not like how they are now.

KIM: Were there any extracurriculars you did growing up, or any hobbies?

[00:07:43]

BELLE: Yes, I liked sports. I would go to sporting events all the time. I had season tickets to a lot of—because it was Chicago. I would go to baseball, football, hockey games a lot. One of my best friends showed dogs so I would go with her to dog shows every weekend and help her, so I did that a lot. Sometimes the dog stuff would bother me, sometimes it didn't. But I wasn't allergic to dogs. I loved pets and stuff like that. I went to the movies a lot. Watched TV. I was more like—I liked sports. I missed my sports. We don't have sports down here.

KIM: What type of sports do you like?

BELLE: Almost anything. I played softball until I hurt my knee. Then I liked going to—I had season tickets to baseball, hockey. I like football. I don't like basketball. I like football.

KIM: What kinds of dogs did your friend show?

BELLE: Doberman pinschers.

KIM: Okay. Are you a dog person?

BELLE: She still does it.

KIM: Okay, well that's nice. I'm more of a cat person but—

BELLE: What?

KIM: I said, I'm more of a cat person, but I like dogs too. Dog shows are, I think, more fascinating than cat shows.

BELLE: Yes. Well, yes, she's been doing it since—she's two years younger than me. So, she's been doing it since she's been twenty years old. She's been in it a long time. Yes, I used to help her. We used to go to dog shows all the time on the weekends.

[00:09:39]

KIM: You said that you lived in the Chicago area for about forty years?

BELLE: Yes.

KIM: So, you must really like that area, then.

BELLE: Well, that's where my parents were from, so I just never—because I didn't get married until I was forty. That's where my family is from, so I just stayed there. But I love to travel, I would travel all over. I've been all over the world. I didn't really have any issues when I was younger, traveling. But I do now. Yes, I love to travel. But now I can't. It's hard.

KIM: I imagine, yes. Well, especially now, too.

BELLE: Yes, especially now (2020 COVID-19 pandemic).

[00:10:27]

KIM: When you were living in Chicago, you said you bought your parents' home—your childhood home. Were your parents also living with you there?

BELLE: My dad was. We'd gotten married and then I bought the house, and then my dad was living with us. Then we had a chance to move down here to (the South), and then he went to go live with my sister.

KIM: Oh, I see. Did you move (to the South) for work or social stuff, or?

BELLE: Work, warmth, switched jobs, just needed to get something different. So, we moved down here.

KIM: Yes, I think switching for warmth is always a good reason.

BELLE: Yes. Don't have to shovel snow.

KIM: Yes.

KIM: I'm just looking through my questions.

BELLE: No worries. Yes, I have the thing that you sent me, too.

KIM: Awesome. You said, after you graduated high school—did you start working?

BELLE: Yes. I started just in an office, then learned accounting and started doing accounting for a company. Then, left that company and went to another company and did their accounts payable, receivable, and payroll for a long time. Then I went to another company, and then I was getting stressed because it was getting to me, so that's why we moved.

KIM: Did you like the kind of work that you did up until that point?

BELLE: Yes. And then it was just getting too stressful.

KIM: I see. So, you taught yourself how to do accounting?

[00:12:34]

BELLE: Yes. I took one class. I took one college class. Most of it's by (computer system), it's what (the company) uses as a computer system. Then I just did most of the basic stuff. Then there was a controller over me and then there was an accountant. I did mostly paying the bills and putting stuff—but it's based on what computer system they use. I was very good at learning computer systems.

KIM: Awesome.

BELLE: Yes. So, I basically was self-taught. But like I said, I did take one accounting class in college.

KIM: Still, that's pretty impressive. And, you didn't have any issues at that time with health or anything?

BELLE: No, I just had a bad knee. I hurt it playing softball.

KIM: You said, growing up, you didn't really have any health issues at all either, right?

BELLE: No, not really.

BELLE: Common cold every once in a while, or the flu, but nothing like this.

KIM: Can I walk some things back with you just to make sure I have the timeline right?

BELLE: Sure.

KIM: So, you grew up in Chicago? You said 1963, right?

BELLE: Correct.

KIM: You have two brothers and a sister?

BELLE: Yes.

KIM: You don't remember anything out of the ordinary with your house? Smelling any kind of scents with your house?

BELLE: No.

KIM: You didn't really like school that much, but you liked some extracurricular stuff.

BELLE: Yes.

[00:14:16]

KIM: You liked to do things with your friends like playing sports or dog shows. There's a lot of traveling.

BELLE: Yes.

KIM: Then after high school you worked in accounting for companies for around twenty years?

BELLE: Most of my life.

KIM: Is there anything you want to add to this beginning chapter?

BELLE: I also learned how to ski so I would travel to ski. I skied out west, and then I went to Europe and we went skiing over there. So I skied when I was younger.

KIM: That's nice. Did you go with your family or your friends?

BELLE: My friends. Almost every year.

KIM: That's nice.

BELLE: Yes.

KIM: When did you meet your husband?

BELLE: 2001.

[00:15:17]

KIM: How did you meet him?

BELLE: Online.

KIM: After you got married, then you moved (to the South)?

BELLE: Yes, we got married in '03. And we moved in '05.

KIM: Two thousand and five. Okay. You said in 2005, that's also when you started noticing—?

BELLE: No. '06, '07 is when I started—when I switched—in Chicago, I worked part time at (the company) stores.

KIM: Oh, okay.

BELLE: And (the company) sold them. They said, if you wanted to stay with the company, we had six months from when they sold them. We had just gotten married and he said he didn't want to live in Chicago his whole life. So I said, "All right, well, let's go to (the South)." I was able to transfer down here to. I started in merchandise. When I was doing merchandise, I was okay. I started having problems when I became a concierge.

KIM: I see.

BELLE: That was like, '06, '07.

[00:16:35]

KIM: Can you walk me through how you realized this was happening?

BELLE: I would go to work and when I would work with certain people, my face would start burning, and my face would break out, when I was close to them. I'm like, "Okay." I had gone for allergy tests before and they always said, "Try to think of what you do every day." So, I was



looking at who I was working with, and stuff like that. I was noticing when I was working with certain people, my face would start breaking out and it would start burning really bad. Then I figured out that they were either wearing perfume or cologne or body spray—this one girl had a body spray that bugged me. So, I sort of figured out there, and then I started going to allergists, but they couldn't help me because they thought I was nuts. They didn't do chemical testing. A lot of allergists don't do chemical testing, which they need to do that. Because a lot of people don't know that that's what's making them sick—the chemicals they're using in their homes.

KIM: Yes, that's definitely something we've heard a lot from people we've talked to, going to an allergist first and thinking it's allergies, and then not realizing it's MCS (Multiple Chemical Sensitivity) until later.

BELLE: Allergists don't test for—because you can't treat it, so they don't test it. I think they should. So hopefully maybe out of this, they'll get some more allergists to test.

KIM: You said that the allergist thought you were crazy?

[00:18:33]

BELLE: Yes, I'd asked him, I said, "When I'm around perfumes and colognes that they make me sick." I said, "Is there any way of testing for it?" I brought in my friend's—all her perfume and cologne. And he goes, "Oh, no, there's no way to really test you for that." And I'm like, "Okay." So, I stopped going to him. Then I went to another allergist. She had said that, "No, there really isn't anything to test." And I'm like, "Okay." Then she gave me something for my face, to put on, which I wore for a really long time until my dermatologist told me not to wear that anymore. I would put that on my—so I had like really nice—because everyone's like, your skin's really nice. It was a lactic cream that I would use. So, I have really nice skin. But, otherwise, I figured it out on my own.

KIM: Yes. How long did that take?

BELLE: But you have questions, so we'll go through your questions.

KIM: Yes.

BELLE: The doctors really didn't get it. Even the people that I worked with—when I said, "Hey, your perfume is bothering me," they're like, "Oh, no, it doesn't." And I'm like, "Yes, it does." They didn't get it either, and they didn't care.

KIM: That's too bad.

BELLE: Yes, that's what is bad is that people don't care.

KIM: Yes. So, they just continued wearing—?

BELLE: Yes. Yes. And my managers didn't care.

KIM: Okay, so it's something that you had brought up to your managers.

BELLE: Yes, big time. Big time, because they did have a rule about perfume and cologne, but it was really vague. It was on how it was interpreted. And I lost, because I had no proof.

[00:20:36]

KIM: Okay. It sounds like they weren't very open to this idea of a fragrance-free office or MCS or anything.

BELLE: Right, because nobody knew about—I was the first one to really say something about it. You know what I mean? I call MCS the new gluten. When people were saying they had gluten allergies? Everybody thought they were nuts.

KIM: Yes. People didn't believe them or thought it was a fad.

BELLE: They didn't believe them. Right, right. That's what I say MCS is. It's the new gluten. And then people go, "Oh, okay."

KIM: That is a really great analogy.

BELLE: Yes. Because when people started saying they had a gluten allergy, we were like, "What's gluten?" That's how I compare it to—

KIM: How did you discover you had MCS on your own, then?

BELLE: The internet. I just started Googling. I found some articles and then I found this professor from Australia, Anne Steinemann. I don't know if you've heard of her?

KIM: Yes. A lot of people have been mentioning her.

BELLE: Yes. Go on her site, my name is on there. I have one of the comments—I'm on her website. She's a professor in Australia who has been studying this for a long time. I use her studies and stuff all the time. I send them to people. I've emailed her a couple times, and she emails me back. She did a talk—I belong to Friends of MCS, and she did a talk on one of their phone call things, like your person did. But I wasn't on that one, because I was busy. But that's why I emailed her. Yes, I use her stuff all the time. You need to Google her. She has a lot of good stuff on there.

[00:22:48]

KIM: Yes.

BELLE: Yes, I was just googling it. Then I found out it had a name. My pulmonologist got it. She understood. So, I love my pulmonologist. Because I ended up getting asthma because of air fresheners.

KIM: I see.

BELLE: I inhaled some—because I worked in the public. So, I was exposed to perfumes and colognes from other people. It was hard.

KIM: Did it take a long time for you to find all this research or was it relatively easy for you to figure it out?

BELLE: It took me a while. I would just find stuff and print it or look at it. There's a couple articles that say perfume and cologne is worse than secondhand smoke. I use Anne's stuff a lot. People have done stories about her, too. But, yes, I basically did it myself. Then I had to go to the dermatologist, for something, and I found out my dermatologist has the same thing.

Her office—you are not allowed in her office area without—and you have to sign a piece of paper. You can't wear perfume or cologne in her office at all. When I found out she had it, it made me want to study it more because then I found out somebody else has it. You know what I mean? I always say, "People think I'm nuts." I'm not nuts, but people thought I was because they're like, "Oh, you can't be allergic to that." I'm like, "Yes, you can." It's hard.

KIM: I imagine, yes. Did your dermatologist—since she has MCS—was she able to give you any more information?

BELLE: No, because she really doesn't call it that. She just says she's allergic to perfumes and colognes. I'm the one who gave myself the diagnosis because that's what it was saying on the internet and stuff like that. Then I got my pulmonologist to start saying that's what I have. Then I finally got chemical tested last year, in January. I'm allergic to five major chemicals in everyday products. Under those five chemicals are eighty-one other chemicals.

KIM: Wow.

[00:25:42]

BELLE: I have to use an app. I have an app. It's called ACDS CAMP (American Contact Dermatitis Society Contact Allergen Management Program), that can tell me what products I can use.

KIM: Interesting.

BELLE: I got that from my dermatologist.

KIM: Okay. So, she recommended that?

BELLE: Yes. It has the five things I'm allergic to.

KIM: Awesome.

BELLE: I can email it to you. I can email you the list.

KIM: Okay, thank you.

BELLE: Then, I could go under hair, and then go, what shampoos I can use. Then this is a list of all the shampoos that I can use, but even some of those made me sick. Even though it says it's "all natural," that still doesn't mean it's—it still has a smell. It took me a long time to find a shampoo I could use. The one I was using, I found out was making me sick. I had to change everything.

KIM: So, after you were first exposed to these perfumes and colognes from people at work, was it after that, then it was shampoos that started making you sick and then other things started making you sick?

BELLE: No, it was more—it was just scented products.

KIM: Ok.

[00:27:07]

BELLE: Then one of my managers wore a musk. Really bad. I ended up using a telephone after they did, and then my face broke out really bad. After that, it was getting worse. Then, like I said, after they started using air fresheners—and then I was dealing with people from other countries and stuff like that, wearing perfumes—coming up to where I work. And then I found out some deodorants make me—like my husband's deodorant that he was using was making me sick. So he had to switch. He wasn't happy. I'd have to find different soaps that I could use, and stuff like that. It was rough.

KIM: You talked about how your allergist was dismissive, but your pulmonologist and dermatologist were pretty supportive?

BELLE: Yes. My pulmonologist more than my dermatologist. My dermatologist would just treat me for my skin, where my pulmonologist would treat me for my allergies and my asthma. I did have an ENT (ear, nose, and throat specialist) that was pretty good, because I would have ear issues and stuff like that, and sinus issues, because I get different reactions to different things. It's not always the same reaction.

KIM: Okay. Have you found most people in the medical field to be somewhat supportive of you or—beside your allergist—or has it been a mixed bag?

BELLE: I do have a new ENT. He was intrigued because he's really never heard of anybody that had that issue. But, he doesn't know how to treat it. It's hard to find people that know how to treat it, but you can't really treat it. You just can hide the symptoms. It's not like a regular allergy where you can get allergy shots.

KIM: Yes.

[00:29:39]

BELLE: You just have to stay away from it. But, yes, my pulmonologist is the best. I love her. And my one family doctor that I used to have—he was pretty cool, too. He understood that it was bothering me, but then he left so I didn't see him anymore. Yes, the allergists are really bad. They don't get it. I'm like, “You're an allergist, you should get that.”

KIM: Yes, it's definitely—it's great that you have at least some people in the medical field that understand what you're going through.

BELLE: Right.

KIM: That's great that you have a good pulmonologist.

BELLE: Yes. And there's some people that—their doctors think they're nuts. They don't get it. I'm glad you guys are doing this. Hopefully, it will make it aware to more physicians, too.

KIM: Yes, that's the goal, to bring awareness to this issue. Did you say that you had to quit work because of MCS?

BELLE: No. Not, well, so—where I worked, it was really bad. But then I hurt my knee through work. Then they added the air fresheners in the bathrooms. I had to fight with them to get them to remove them. That took a long time. Even just fighting them to get people to stop wearing their perfume was bad. No, I had to leave—I had a workman's compensation claim. So, they bought me out of my workman's compensation. That's why I don't work there anymore. Another issue was, they couldn't find me a job where they wanted to remove the air fresheners. So, even though it was in my restrictions—they know the rules around the ADA (Americans with Disabilities Act of 1990) laws. That was another thing I did. Before I got the restriction, I learned what my rights were, because I worked for such a big company. I looked up all the ADA laws. I started talking with them. I think they're there either in—they're called JAN (Job Accommodation Network). They helped me a lot with the ADA laws—at least working with disability. Especially after I was diagnosed with asthma, because asthma is a disability, whereas a lot of MCS issue stuff isn't a disability, which I think the government needs to re-look at that. But because I have asthma, that is considered a disability, my pulmonologist diagnosed me with asthma. I'm on inhalers. I've got a whole thing of stuff. I have to bring it with me every day, like if I go out. I have a backpack with all my medications in it because I never know what I'm going to need.

[00:33:01]

KIM: Yes. And you said that it was a battle at work to get them to remove the air fresheners, things about perfumes and cologne. Can you go into more detail about that?

BELLE: What their thing was—it was a personal issue instead of a workman's compensation issue. It took a long time to get them to honor that restriction. Then it was how my doctor originally worded it. I had to have my pulmonologist—I had to say “fumes,” instead of—yes, we had to word it just right for them to—So, it's hard. I can't go to bathrooms, even here, now, it's hard. I can't use a lot of public restrooms because they use air fresheners. They don't get it, that they're bad for you.

KIM: Yes. I know we talked a little bit about your family reacting to it. Were they initially skeptical at first or did they believe you right away?

BELLE: Well, I lived down here, so they were all up in Chicago. So, just my husband—I mean, he knew there was an issue. I don't know how he—It took him a little bit to understand, but now he's more supportive and everything and even stuff now bothers him. He'll smell it. He'll go, “Okay, you don't want to go over there.” Or, I'll have him—if he goes to the restroom, I'll go, “Okay, was there an air freshener?” And he'll say yes or no. Because if it's in the men's, it's in the ladies. Or, he'll say, “Okay, you don't want to go over there, that smells really bad.” Now it's

affecting him because it affects me. He's more aware of it now. He's had to change his life, like stuff he's used and his lifestyle, too. Love him for that! I'm hoping he'll hear. He's home.

KIM: I know you said that you're the one who informed your niece and your sister about MCS, too. What was that like? I guess you had—you just told them about your symptoms and then they realized that they had it, too?

BELLE: Yes. I was telling them, "Yes, I just found out that scented products bother me." If I'm around people with perfume or I'm around stuff with that—and my sister's like, "Yes, that stuff bothers me, too." And I said, "Oh, well, I guess you've got what I got." Then a couple of my nieces were like, yes, they would get migraines. I don't get—I get some kind of a tension headache. I have it in the back of my head. I don't get a migraine, but I do get—it hurts, and it will last, like, four days. It bites the big one. But, talking to them, I said, "When I'm around people with perfumes and colognes or scented products, I would get sick." And I said, it actually has a name now. They were like, "What?" I'm like, "Yes." Then a couple of my nieces, when I would talk to them, they're like, "I have that issue." I'm like, "Well." So, they started now not using scented products and stuff like that. At their work they try to get the people to stop. Yes, it was sort of like, when I found out that they have it, too—it could be hereditary. Well, yes, because it's—one is my brother's daughter and one is my sister's daughter—they have the same issue. So, it could be hereditary. And like I said, my sister has the same issue.

[00:37:10]

KIM: How old are your nieces?

BELLE: They're in their thirties, and then my sister is ten years older than me, so she's in her sixties. Like I said, when we were younger, we didn't have that—I didn't have that issue. It started more down here and being exposed to it a lot, I think, activated it. Yes, we had to change our lifestyle, so it stinks.

KIM: Yes. Were your friends receptive to the—?

BELLE: Some were, some weren't. Some, I would tell them, "Hey, you know, we're going out. Do you mind not wearing any scents, no perfumes or colognes?" Then they would use a scented hand lotion, and I'm like, "Okay." Then they'll go, "Oh, I forgot." And I'm like, "Okay, well, then, I'll get sick." Then, after a while—my friends now get it. At the beginning, some of them—they got it, but then, yet they didn't get it. Then if we would go out they would go, "Oh, I forgot." I'm like, "Okay, so—" Even though they didn't put perfume or cologne on, they'd still use the hand cream that has a scent to it, or they would use hand sanitizer. So, now they're going to use hand sanitizer. I can't use hand sanitizer. I have wipes. Hand sanitizers—I could smell stuff a mile away. I can go, "Yep, yep, yep." It's hard. I tell people it's like if they have a peanut allergy and they come over to my house for dinner and I made brownies for dessert, and I accidentally put peanuts in it and then they had a reaction. And then I said, "Oh, I forgot." That's what I tell people if they forget. I try to go "Hey, well, what if it was you, but with something different? And then I made you sick, you would be mad at me." I try to put it that way, give them an example. "Hey, well, you have a peanut allergy." Because everybody is allergic to peanuts. They

accommodate peanut allergies. Why can't you accommodate this? This is bigger than, I think, peanut allergies, because a lot of people don't know that they have it. That's all we see on TV, "Oh, use air freshener, Glade, or use this to make your house smell fresh." Well, yes, it's making your house smell fresh, but is it also making you sick? I think the government needs to put more regulations on scented products. But there are none.

[00:40:35]

KIM: That's another great analogy you have, you have a lot of—

BELLE: I've been doing this for five years. So I have been, like—my husband said I was fighting a losing battle, but I'm finally getting little victories here and there. Even the company I used to work for—now I don't work for them anymore. I'm now an annual pass holder, so they listen to me more. They now took their air fresheners out of their companion bathrooms. Do you know how much of a victory that was for me?

KIM: That's huge.

BELLE: That's huge. That's huge. I write letters, and I don't write them to customer service. I write them to the CEOs. I go to the top, because it's their company, they're in power. They wouldn't do anything for me as a worker, but as an annual pass holder, I finally—five years of fighting with them—got them to last year, finally, to take them out of at least the handicapped companion bathrooms. So, I can go to the bathroom.

KIM: Yes, I was actually just going to ask about that. When you mentioned as an annual pass holder, they took you more seriously. As a worker, they didn't see that, but then as a consumer, they're like, "Oh."

BELLE: Yes, they don't care. You live in California, and you have (the company) there. Yes, they don't care about their workers.

KIM: Yes.

BELLE: No, and they know the rules around the ADA laws. But, as an annual pass holder—and actually, it was one of the secretaries to one of the vice presidents that actually helped. I thank her all the time. Yes, because I used to—I would have to wear a mask. So I have masks for all of this that's happening right now. I have masks. People would look at me weird when I would go into bathrooms because I would have to wear a mask. Everybody would think I was sick. Now I put on it, "I'm not sick. I'm allergic to scented products."

KIM: That's clever.

[00:43:00]

BELLE: Yes, I was tired of people looking at me. Little kids going, "Why is she wearing a mask?" So, I have masks for what's going on right now, which is sort of nice. When I go do grocery shopping, I wear my mask. It took me a while to find masks that—I mean, they help but they don't help, because a lot of masks have carbon filters in it. I found out I'm allergic to the carbon filters.

I had to find masks that didn't have carbon filters. It took a long time to find them. I usually have to wash them out first, rinse them out, because whatever they put in it would irritate my skin. Yes, been doing this for a while, been studying it for a long time. So, when I saw you doing this, I'm like, "Yay, I need to participate in this."

KIM: Have you been part of any online communities or forums for people with MCS?

BELLE: I did join the Friends with MCS—last year? Yes, last year. Sometimes I am able to do their phone call, sometimes I'm not. There's a woman in Minnesota that I'm in contact with that—she has the same issues and we're around the same age. We'll try to do phone calls because it's nice to talk to other people who have it. Because it's stressful, and at least they know what you're going through, and they don't think you're nuts. But best thing I tell people is to make sure they get chemical tested to prove it, because then it's documented that, "Hey." That was the best thing I ever did was to get—my dermatologist chemical tested me. Then I can go "Yes, here, this is what I'm allergic to. Yes, this is what makes me sick. It's official because I got tested." Everybody before would just say, "Well, you never got tested. How do you really know that that's what's making you sick?" I knew it just by process of elimination because of having to do that for regular allergies, which I don't have. That's what they originally thought it was. They would say, "Well, write down what you were doing" and all this other stuff. Then I was like, okay, wait, I just went here and this—I got sick. Then I just put two and two together one day and went, "Oh, that's what's making me sick." So, I self-diagnosed myself but then getting chemical tested last year was the best thing I ever did.

KIM: Yes, that's interesting that people feel like they need some sort of formal—

BELLE: Proof.

KIM: —recognition. Yes, formal proof, rather than you knowing what's going on within your own body. Yes, that people need that formal proof to be able to believe something, right?

BELLE: Well, no, it's not just for me, it was just—

KIM: No, for other people, yes.

BELLE: Right, to make other people aware that, "Hey, this is what's—I'm not crazy." I am sometimes, but I'm not crazy about this.

KIM: The only way to be taken seriously is if you have some sort of doctor's note and then people pay attention—

BELLE: Yes, well, I have the app on my phone now so I'll just go, "Hey, yes. See, this is my app. This is what tells me what I—" They're like, "Wow." Yes, it was the best thing I ever did was to get chemical tested.

[00:47:01]

KIM: Yes. I want to ask some questions about daily life now because one thing you had said that, I think, is just so interesting—it's such a big part of your life that you can't use public restrooms without having to really do something—



BELLE: I can't even go to the mall anymore. Do you know how hard it is to not be able to go to the mall anymore?

KIM: Yes, that's tough.

BELLE: My husband loves going to the mall. I cannot go to the mall. I miss going to the mall. I can't go to indoor malls. I can go to an outdoor mall, but I can't go to the indoor mall. Our big mall here—I can't go to it because there's too much fragrance and too many people wear perfumes and colognes. So, what's my daily life like? Well, it depends on if I'm going to be working or not working or if I'm going out. I always have my backpack with all my stuff in it. I always have to bring a mask with me because if I do have to use the restroom, or if I am around somebody in line—like, if I go—before all this (COVID-19) happened the past couple months, if I would go grocery shopping and somebody in line, or the person ringing me out, had perfume on, I'd have to put my mask on because I would get sick. Then I started complaining to these companies, stating “Hey, I can't use your bathrooms.” Or, I would start telling them—if it was at a store or something, I'll tell them, “Hey, I'm allergic to this. You should tell your people—Yes, I understand why they need to wear it, but they don't need to swim in it.” You know what I mean?

I do live in an area where it is a lot of Hispanics. It depends on, too, what nationalities you are. Especially when I did work—when the British people would come or the people from South America—from different countries they use deodorant, but they think putting on more perfume makes them cleaner. My best friends live in England and I had to get that into their head that, no, that's not what it (does). When I went to visit them, they had to change their thing for me, too. Her husband had to change his deodorant because what he used would make me sick. Yes, a lot of different countries—because of where I worked, the people had perfumes and colognes on. Then that's when I would find out that it would bother me.

But, yes, going out, I have a backpack full of my inhaler, nasal stuff, eye drops because I would have eye issues, masks. Then, also, we figured out, too—we just figured this out over the summer. I was waking up sick. I'm like, okay, well, I didn't do anything. What did I do? Well, we would go out, or he would go to work, or he would go someplace—it would get into your hair. People don't get it that it gets into your hair, it gets on your clothes. Now, when we get home, if we go anywhere, we take what we have on, off. We put our PJs on, and we take a shower. We have to take a shower at nighttime to get that off. If I don't, and it gets on my pillows, I get sick. I wake up in the morning and I'm sick. Then I try to change my pillowcases, two or three—more than I normally do. Then I wash my pillows once a month. I'll be sleeping and all of a sudden I'm going, okay, I'm getting my headache or I'm not feeling good. Then the next day I'll wash everything. It's now just a routine of ours, that when we get home, he'll take a shower, I'll normally just wash my hair, but we have to change clothes. Now it's just part of life.

[00:51:35]

We had to change different products that we use in the house. Cleaning products bothered me. I got this from Anne Steinemann—hydrogen peroxide. I use that, and it's cheaper. It's only eighty-eight cents at Walmart. You mix that with water. It cleans and disinfects just as well as all the other stuff and it doesn't smell. I have to dilute it more, now, because it's bothering me a little bit

more but—who else had?—my air conditioning people. I have to change my air filters more. The people I bought my air conditioning from—his wife had the same issue. So, he got it. The stuff they use to clean my air conditioning unit, they had to dilute it really bad because if they didn't, I would get sick. It would go through my vents and get sick. Then I use air purifiers—I have three air purifiers. I have one in my garage and then one in my living room and then one by my computer. That helps a lot. Yes, we just changed—even though the product might say unscented, it still has a scent to it. I used to use Secret deodorant and it was unscented and then it wasn't on my list. Then I found out, yes, it was making me sick because there still is a fragrance in it. You have to make sure you buy fragrance-free. Make sure it's fragrance-free, not unscented. There's some unscented products I buy, but I look to see—but most of my stuff is fragrance-free. Even though it says it's all natural or essential oils—On Anne Steinemann's website, she has a study about that, too. Because people go, "Well, can't you use the all-natural or essential oils? Do they bother you?" I'm like, "There's still chemicals in them, people." There's still a scent, there's still—they don't get that, either. Yes, it's hard living with it.

[00:53:51]

My symptoms depend on what I'm exposed to, and how I'm exposed to it. Like I said, I could have eye issues—my eye can get all swollen. I have a hard time seeing, it gets dry. I can have ear issues. I can inhale it, then I have breathing issues. I have a breathing machine, so I have to give myself a breathing treatment, besides using my inhaler. I get sinus issues, I get headaches, if it happens. Yes, it just depends on what the product is. I wish people would stop wearing perfume and cologne to movies. Like, "Hello!" We actually had to change our seats once, before they closed the theater, because even though they're assigned seats, the person next to us came late and they were swimming in it and we had to actually change seats because they—and they don't get it. Sometimes it's bad and sometimes it's not but I try to avoid the situations. Like I said, I don't go to the mall. Which I miss, but—and like I said, using a public restroom. Or, I can't eat at certain restaurants. I used to love going to Cracker Barrel. Can't walk into a Cracker Barrel. I will get sick. Can't go into Bed Bath and Beyond. Can't go into Michael's. I can't go into some stores because they use scented products. The companies don't care. I have written to a lot of the companies. They don't care.

KIM: Do they respond to you or do they just never say anything—

BELLE: Some do, some don't, I did have an ADA lawyer assist me in writing a semi-legal letter to these companies. Then I stopped because a lot of them weren't answering me. A lot of them will—"You're the only one complaining about it." I said, "Yes, but it's still—to me, it's a disability." I think the government needs to see that, even though I have asthma, MCS, any symptom could be a disability. They need to recognize that, and they don't. I'm trying to fight for it and nobody wants to help me. There's different laws in California (than there are in the South). I found out there's different laws in California. There's actually a lawsuit going on in California regarding scented products.

[00:56:38]

KIM: Okay.

BELLE: Up in San Francisco.

KIM: Yes. I think someone else had mentioned that one, too.

BELLE: Yes, there's a lawsuit going on in California. They were going to help me, but then because they're out of state, it was hard. So, they couldn't. They couldn't.

KIM: Different laws and, yes—

BELLE: Yes. They wanted to help me so bad. They said, “If you ever come to California and you get sick, let us know.” I’m like, “Okay, I'm not coming, so.” Yes, it's hard. One of your other questions here is how have—accommodations. I used to love to travel. I would always say, “Have passport, will go anywhere.” I love to travel. I can't anymore because I don't know if that hotel or the airplane. If someone on the airplane is going to wear perfume or cologne. I'd have to wear my mask. Over the summer, we had to go to Denver and just calling up the hotels to get a room specially cleaned—they thought I was nuts. They didn't get it. They were accommodating, but I still got sick. Even after I got sick, they were still accommodating—because I found out even though they cleaned the room, the sheets, what they used to wash the sheets in, made me sick. I was glad I brought my own laundry soap. The one hotel actually gave me money to wash the sheets with my own (soap) and then I was okay. But they at least cleaned the room. I ended up getting a handicap room, which, they now are taking the carpeting out of them. A lot of the hotels are. They were finding out the carpeting is actually bad. It's better to have tile. Even though I have carpeting in my house. They at least did a special cleaning for me. Then, the one hotel—we were only there a couple nights.

Yes, they don't get—the travel industry. A lot of the hotels now have air fresheners in their lobbies, because they want their guests, or, their customers, to have this great experience when they walk in, to smell something—not knowing. So the company I used to work for, I can't go to any of their hotels because they have air fresheners in their lobbies. They don't get that. Even other hotels and chains and stuff like that, they'll have—my friends were staying at Universal. We walked into the hotel, and I was getting sick. I had to run through the lobby because they want the guests to have this great experience and smell all this stuff, but they're not knowing that, hey, you're actually making your employees sick and you're actually making your guests sick. They don't know that that's what's making them sick. It's hard to explain it to people. I'm hoping this study will at least get it out there that the hotel industry needs to stop using air fresheners in their lobbies. And it just started—I'd love to know who, like I said, 2013, 2014. Somebody is pushing air fresheners and whoever it was, I want to shoot them, because it—the first twenty something years of the company I worked for, didn't use them. Well, why do you have to use them all of a sudden? Someone talked them into using them and they don't get it. But at least I got them to take them out of their companion bathroom. So, at least—once it opens back up again, because—I keep circling back. What other questions would you like to ask? Like I said, I get off topic.

[01:01:03]

KIM: No, this is great. Are you currently working in a different company now?

BELLE: I actually filed for—once I got let go from the company I worked for because of my workman's comp claim, I was going to have a hard time finding a job because interviewing with somebody, I can't tell them my disability because it's against the law. Once I got into a company, it was like, I would have to fight like I did with the other company about people wearing perfume and cologne and getting an air freshener out of the bathroom and stuff like that, and just calling in sick because—or going home sick. FMLA (Family and Medical Leave Act) helps, but you still have to work so many hours to get it first—and I can be good at work, but then maybe go out to dinner when I get home and have to use the bathroom in that restaurant because I'm old. And, I would get sick. Then the next day I'd have to call in because I was sick, because I got exposed to something. Then they would go, “Well, (Belle) is calling in sick.” At my old company I had FMLA, but at a new company you have to wait. So, if I go and get a job, I would probably lose it because I would be calling in sick or leaving work because either somebody would make me sick, and then, trying to get—explain it to them, my illness. I didn't want to have to go through that all over again. So, it's hard finding a job with somebody with MCS, just because of all the restrictions that you have.

I'm older, but a younger person with it, who probably doesn't know, will probably have a hard time finding a job because it depends on what their reaction is. I at least have asthma, where asthma is a disability, so they have to honor it—reasonable and customary accommodations. Taking that air freshener out of the bathroom would be a reasonable accommodation, but some of the other things they might not do.

[01:03:27]

I've heard some people had to leave jobs because their work wasn't accommodating to them because they didn't believe them. That's why I want to make sure I tell people, “Get tested.” Then you have a legal document from a doctor that says you are allergic to these products. I did apply for Social Security Disability. I'm in the midst of two years battling with Social Security Disability because they didn't think I was sick enough. I actually went to court three days before I went—two days, no, a day before we went on lockdown. So, in March, I had my court date with Social Security and actually got sick during the court date, during the court hearing. I went to lunch—I ate lunch near where the court hearing was and then I had to use their bathrooms and they had air fresheners in their bathrooms so that one made me sick. Then when I went into the room that we had our hearing in, somebody had perfume on. It was either the judge or one of the other ladies because it wasn't the court reporter, because she came down the hallway. I could smell perfume like a mile away. It wasn't her. It was one of the other two. They had just cleaned the room because all this just happened with the coronavirus. Whatever they used to clean the room was making me sick. In the middle of my hearing, I had to ask the judge, “Can we stop for a second?” I had to use my inhaler because I had a hard time breathing. I'm waiting to hear for my decision if I got it or not. I had to fight with them for two years because they didn't think I was sick enough.

I have asthma, and if I did have a bad reaction, I have my own breathing machine. I can do my own treatment. Why should I have to go to the hospital for a breathing treatment that I can do at home? They didn't get that. They were like, “Well, you didn't go to the hospital enough.” Well,

first of all, my pulmonologist said to stay away from the hospital because I could pick up something else. That's why I have a breathing machine. When people say they're having an asthma attack, it's like, well, are you at home? Don't you have a breathing machine? Do your own—there are days when it—yes, I don't have my inhaler, but it's not that bad where I have to go to the emergency room. Then, as soon as I get home, I'll do a breathing treatment.

So, right now—and then I work part time at my husband's work, where he works. Because it's a warehouse, I was working a lot, but then I was finding out, because it's a lot of guys, they wear Old Spice, and the owner actually wears cologne. We took the air freshener on the bathroom but I was asking them if they—I can't tell people what to wear. I could tell a work (place) they have to take the air freshener out of the bathroom, that's law. But, working with you, I can't tell you all, you need to change your laundry soap because the laundry soap you're using makes me sick. You know what I mean? I work on the days where there's not a lot of people. It's usually—I work two days a week. And, hopefully get my Social Security.

I also have called a couple of my local representatives to try to see about getting laws and stuff regarding air fresheners and scented products and none of them seem to care. It's a fight. What my ADA lawyer told me to do was actually to write letters because then you have it documented, instead of calling. I have folders of everybody I call and contact and I have all the letters and who I send it to and what, and even the representatives. I usually send a copy of one of Anne's studies, like "The Ten Effects of Air Fresheners"—why they're bad for you—with the letter so that they can see, hey, there's this professor, she's been doing it for years, has done the study on, they're bad for you. The society, because we were brought up using them, they don't get it that it can make somebody sick.

[01:08:14]

Yes, I am an advocate. I fight all the time. I try to help people, which, I have. I have helped a couple people find out that they have this issue because their doctors couldn't help them. Just recently, some friends came over. She had hairspray on. She was wondering why I wasn't sitting close to her. I had told her—because I don't always like to bring it up because I don't want people to think, well, I'm going to go hang out with (Belle) and that's all she's going to talk about is her allergy. I try not to bring it up with new people unless something happens. Her hairspray was bothering me, so I had to bring it up because she had asked. Then he—her husband—excuse me. We started talking, and he was having a hard time breathing and he was having issues and he had seen—for like, five years—and he had seen all kinds of doctors and nobody can tell him what his problem was. My first question to him was, "Do you have air fresheners or do you use strong chemicals when you clean in your house?" They're like, "Yes, we have an air freshener in our kitchen." I said, "As soon as you get home, you take all of that, you put it in a box, you open up your windows of your house, let it all air out and everything, and five to one, you will feel better." He's never felt so better in his life. He said he can breathe in his house now, because they took out all the air fresheners and they changed the cleaning chemicals that they use, and they're starting to change the chemicals that they use. He can actually breathe now in his house.

So, I try to educate people, too, saying, “Hey, is this why you're getting sick?” Or people with—if I find out somebody has asthma, and I say, “Well, do you get sick in your house?” If they say, “Well, yes,” then I'll say, “Well, do you use scented products? Do you use scented laundry soap?” I try to educate people too, and I tell them to go on about—you need to stop using these products. If you're getting sick in your home, it's something you're using in your home. If you're getting sick outside, then it's something outside. Sometimes I'll go, “Okay, wait, why all of a sudden am I getting sick at home?” Then I'll go, “Oh, yes, I had, like, the cable guy was here” and I was like, “Oh, yes, he had something on.” That's another thing—when people come to fix stuff. They'll wear—I'll try to tell them I need somebody that doesn't have it, but it's hard. There was one time I wouldn't let a guy in the house because it was too strong. I said, I don't feel like having an asthma attack.

Yes, it's hard because a lot of people don't get it. Just with our society and how we were raised. It's advertised all the time, and it's rough, but I try to fight for it. But now, with all of this going on in the world, it's down on the burner now. At least I'm glad you guys are doing this study so that hopefully once it's done it will bring some awareness to people and maybe get something changed, and help us. It's like a peanut allergy. That's my lingo of how I explain it to people. You won't let the kid eat peanut butter, or they can't serve peanuts on airplanes anymore. Why can't you take the air freshener out of the bathroom? They're not as safe as people think they are. Like I said, my husband thought I was fighting a losing battle, but I'm getting little victories one by one. My thing is if I can help one person feel better and not have to go through what I went through—our friend's husband was sick for five years and nobody could help him. Nobody knew that that's what the problem was. I text him, “All right, how are you feeling? Are you breathing?” And he's like, “Yes, it's awesome.” Those are my little wins. When I heard about you guys, I was so excited.

[01:12:58]

KIM: Yes, and even those little wins, I feel like are huge, too.

BELLE: Oh, yes, it is. Yes. Like, even my chiropractor, I have to stop going to them because—or, I have to bring my own stuff because they won't use unscented laundry soap. I'm like, “It's the same price, people. It's the same.” You can get it. The cheap brands are making it now—Free & Clear. A lot of the brands now are making it, Free & Clear, and stuff like that. Oh, that's another thing I've noticed—I can't use dryer sheets anymore. Some products that I used to be able to use, or are on my list—I can't use the fragrance-free dryer sheets because what's happening is they're making the packaging so thin to save money that—and they're putting them next to all the stuff that are scented—that it's going through the boxes and contaminating the unscented products. So, I had to stop using them. I use fabric softener, but I don't like it, so some of my clothes come out staticky, but I don't care because I just wear shorts and t-shirts anyway. I'm glad I don't have to wear dress clothes. Yes, they don't get that, just—I can't go down the laundry soap aisle. I have to send—if I'm with him, or, I have to put my mask on if I need laundry soap and stuff because I can't go down that aisle. It's so strong and they don't get it that it's contaminating the stuff that is supposed to be unscented because they made their packaging so small.

KIM: Have you tried using dryer balls?

BELLE: I'm allergic to wool. I tried those. I can't. I did try. I don't know. The wool didn't make it. I really haven't tried dryer balls because there are some plastics that make me sick. So, I'm afraid to use the dryer balls. I did buy something I found online that's supposed to help with that, but it doesn't work. Even some of the stuff I bought, even though it says it's fragrance-free, it made me sick. I have to watch what I use and once I find it, it's like, "Yes!" Then the company will stop making it. I'm like, "Why did you stop making it?" I'm trying to get places to take them out of their bathrooms and trying to get people to stop wearing perfume and cologne if they're working in the public with people, but it's a fight. Sometimes I win, sometimes I don't. At least if I make it aware to these businesses, they'll go, "Oh, yes." When I bring up the peanut thing, that's how I do it. If I'm talking to businesses or managers of businesses, and then they'll go, "Oh, okay." What else would you like to know? Sorry, I want to make sure I go through all your questions so that you don't have—

[01:16:51]

KIM: Yes, no problem.

BELLE: If you need to follow up, too, I don't mind. Just send me an email.

KIM: Yes, of course. Well, it seems like this would cause a lot of emotional and mental labor to do all—

BELLE: Yes, I have anxiety.

KIM: Yes, I was actually going to ask if you've ever had any sort of mental health support, either formal, like counseling, or informally.

BELLE: I do take medication, sometimes, for my anxiety. I do have anxiety because I don't know if I'm going to—I can go to a place one time and not get sick, and go the next time and get sick. I can go shopping at Walmart one day and be great. But I can go shopping at Walmart the next day and be sick. So, I don't know what's going to happen to me when I walk out the door. Yes, my anxiety, if I have to go out—Yes. The anxiety of just going out—or our friend's daughter is getting married. I'm not going to be able to go. It's out of state. One, I don't know about the hotel. And then, two, being around all those people at the wedding—love their daughter dearly—But I don't want to get sick, and have to spend all that money going there. I'd rather go and visit them on a time when I don't have to worry about—because they understand and they were just here recently and they actually stayed with us, so they actually saw it firsthand how it affected me. We went out and I had a really bad reaction where we went. My eye was getting all swollen and I had a hard time seeing and I didn't want to drive because they were in the car, so she actually had to drive my car. Because of—but there's sometimes I'm by myself and if I have a reaction and my eye swells up, I'm driving going, "Okay, am I going to be able to make it home?" At least with that—and then she was like, "Wow, I actually saw it now firsthand." They understood it, but now she gets it more because she was with me when it happened and she actually had to drive my car for me because I was afraid to drive because they were with me. That helped with them.

Or, if people come and stay with me, I have to tell them, “I will supply the shampoos, the soap, you know, everything you need to stay at my house. You cannot bring anything scented into my house.” It's hard because they'll bring in hand cream and forget. So, I tell them, “I will supply you with everything.” I even have extra deodorant. Washing clothes, I have to use stuff. Our surrogate son is going to be moving in with us. I told him, I said, “Yes,” so, he gets it. I told him, I said, “Yes, you're going to have to take a shower when you get home,” because he works in the public. He's like, “Okay, I get it.” Yes, this is one of my little bags I carry with me. I have my inhaler, I have eye drops, nasal sprays. Ziplocs are my friends. And then I found out, too, sometimes—this is really gross. If it gets really bad and the mask doesn't help, I take a nose plug. I put it in my nose—because it's only one nostril that it happens to. It's beige, so you don't see it. I've come up with little tricks for myself to help me, so if it's really bad I'll put this in my nose so I don't get sick. Then at least you don't see it. It helps so that I can go places and not have to wear my mask. I've come up with little things to help me, because like I said, I've been doing this for over five years. This is my one little bag of stuff I have to bring with me just to leave my house.

[01:21:59]

KIM: Sounds like there's a lot of self-navigating.

BELLE: Yes. Have you interviewed a lot of people yet, or—?

KIM: I've interviewed a handful, but since I got on this project around—must have been July? They had already been doing the project earlier. I've read so many transcripts of people that they had already interviewed.

BELLE: That's cool. So, now, are you from California?

KIM: I am, yes. I'm actually from the Bay Area, but I've been living in LA for the past five years.

BELLE: That's cool. So, now, you even get it now, even though probably you don't have it. But at least now you know. It's hard to get people to understand what we go through and that it is an issue and there's no treatment for it. Thought there was one. The lady I told you about in Minnesota thought she found a doctor in Wisconsin, but then they stopped. And, it was like, I wasn't going to Wisconsin. I don't know why they stopped. I wish somebody would study how to help us on the medical end, besides what you guys are doing, do a medical thing. What's causing this and why is it—is there something we can do like regular allergies, we're going to get shots or something. I just deal with it day by day. He (husband) deals with it. It took me a while to get him to understand why he had to take a shower when he got home. We just figured that out a couple months—like, last year. But, it took him a little bit to figure out why we had to do that. Then once he did, he got it. He understood. He goes, whatever is going to make me happy. I at least have a great husband that's supportive with (husband inaudible in background)—right, did you hear what he said?

[01:24:31]

KIM: I didn't hear all of it.



BELLE: (To husband) What did you say? Yes, he can't be the person that's making me sick.

KIM: That's really great because I know some people didn't have supportive partners or spouses or family members. That's obviously not—it's not great to have someone who doesn't believe you or—

BELLE: Right. Yes, at least he supports me. And now that, like I said, I got tested, and he understands, and he's seen when I'm sick. I can't go out. I'll just go, “Yep, no.” Or, I'm sitting there going, “Oh, my headache is coming.” I use ice packs and stuff like that. I just think companies and people need to understand. They need to stop using air freshener. Stop using scented products. I thought there was a company that did come out with something—a new air freshener that wasn't scented, but then there was something else in it that made me sick, and I was so mad. I was like, “Oh, somebody invented an unscented air freshener, that would be so great.” Then I got a sample of it and they use something else and whatever they used, that made me sick. I was like, “Oh, man.” I was so wanting to promote that product, and I can't because it made me sick. Because it was unscented. Or, I do use a product. The Febreze, but it's for fabric. I've even called Procter & Gamble who makes it and go, “Can't you put this in a Febreze bottle? Like regular Febreze instead of just calling it fabric?” Then when they came out with a new one, it's called Febreze ONE, where it's—when the commercial first came out it said, “Oh, no perfumes and colognes.” Then I looked at it and it was bamboo scent. It still has a scent. “No, we don't put as much in it.” I said, “But it still has a scent. You don't get it. It still has a scent.” I said, “You make a product that is natural and doesn't—why can't you just market it as a plugin. It does the same thing.”

Yes, I do have products that I can use. Or, another—this is going to sound gross. If you are in a restroom, and you do use an air freshener, don't spray it in the air. Spray it in the toilet, while it's flushing, while it's going down. You spray it in there, so the smell is going with it instead of in the air. When you walk into it and you breathe it—but even, one of the hotels I went to, they had put—instead of the air freshener in the little canister thing—they had it in the toilet like that. Well, it was going off every time somebody flushed. That's too much. So, that was even bad. They did switch, but how often they were having it go off. That's what I tell people, too. I said, “Okay, I understand why they want to use the air fresheners.” But, I said, “You don't need to have it go off every time you open the door. You don't need it to go off every time somebody is in the bathroom. Have it go off once.” Or, make sure the air conditioning is on. You're putting it in a room that doesn't have any airflow so it's not going anywhere. Then they sort of get it. Like I said, I just started fighting last year. But now with this going on, I have to start all over again once everything is back to normal—which, that's going to be a while. Any other questions?

[01:28:40]

KIM: You say you just started fighting last year. Was there something that triggered that to make you—

BELLE: I was tired of getting sick. I was tired of going places and not being able to use the bathroom or going places and getting sick. I first tried to find out the laws, or tried to see if somebody would help me. There is and there isn't. It's an interpretation. Then I was trying to find

an ADA lawyer or something that would maybe help me. Most of the ones here thought I was nuts, so they wouldn't. Same thing that happened when I was trying to get Social Security. They wouldn't help me because they didn't help. I found a company that did. Then I found the attorney in the South. She got it because she investigated, too, and found the lawyers in California. She helped me and that just happened last year. There were a few companies that I did write to. Some of them got back to me, some of them didn't. Then I would just write another letter, or I would call and then I would document when I called, who I talked to, and all the other stuff. Then I started calling my state representatives, but they didn't seem to care. Their people didn't seem to care. Then I went to our local representatives. One took a meeting with me, but didn't seem like they were going to help. Then I called another one and they were like, "Well, we're in the process of doing something," and they didn't care either. My thing is if it was you, you would want the laws to change. But now with all this happening, it's put on the wayside. I was trying to contact my different state representatives, or my local representatives here, where I live, or just try to find anybody that would help. A lot of people wouldn't because they thought I was nuts.

I did find a lady who was really nice, and she helped me a lot, but there really wasn't much, I really—I did file a discrimination suit against a company. We thought we were going to settle, but how they worded their thing, and then how I worded it—and then it went back to the (state's) discrimination board, whatever it's called. They were still reviewing it, and then, all this (COVID-19) happened. Everything I always do gets put on the wayside. We'll see, once everything goes back to normal—because I think they're still working from home. So, they might be working on it. I'm not sure. Yes, I have filed something against a company. I hadn't heard from them. The only time I heard from them was when they got the letter from the (state) thing that somebody filed a discrimination thing against them. Then we tried to—then I started talking to that attorney in San Francisco. Then we thought we would come to an agreement, and then it didn't happen so I refiled my complaint. I'm waiting to hear back because, like I said, this shutdown thing came. The world is thinking about other things, except—so I have to wait. I can do that. I'm trying to fight—I'm trying to get more. That's how I met the lady in Minnesota because the Friends of MCS—I posted it in their newsletter, that I was looking for people in other states to help me fight the fight to get the laws changed. She was the only one that contacted me. The only way we'll make a difference is if—the news station did do a story on me down here, when I did lose my job. Or I—well, I brought it to them not about me losing my job, just about how scented products are bad for you. They actually did a story on it. Then they did another one about how I lost my job. I thought that was nice, that—and she actually understood. I called all three local news stations, and none of them—but then this one did, and she actually came out and we did a story. It got on the air, so if you Google me, it'll come up.

[01:33:53]

KIM: Was that last year?

BELLE: No, it was in 2017.

KIM: Oh, okay.

BELLE: News 9. So, yes, if you Google my name, if you Google me—there are two stories. There is one I lost my job. You don't want that one. There's another one. I think the one that comes up is the one that I lost my job. If you do News 9 and scented products, it should come up. Because it was News 9, and it was in 2017 that they did the thing. Even then, the news people were like, “Wow.” They didn't know it. The reason why they did it was because their general manager, when she brought the story up to them, he went, “Maybe that's why I'm getting headaches.” He was wondering why when he was at work he was getting headaches and stuff like that, or he would have a meeting and he would not feel good. Well, it's because his people that he worked with were wearing perfume and cologne. So, he let her do the story. That was cool. Oh, another thing, too, is—I don't know if you know this but, the CDC—the Center for Disease Control that's handling all the—they actually have a policy that no perfume or cologne are allowed in their buildings.

[01:35:20]

KIM: They have a fragrance-free office?

BELLE: They have a fragrance-free building, yes. The CDC in Atlanta has a fragrance-free policy, and it's on Anne's website. So, if the CDC is telling you that they have a fragrance-free policy, what is that telling you? You can't wear it into their buildings. You can't wear it to any meetings. If you go on Anne's website, it's on her—she has it in her website to see their policy that they have. So, the CDC in Atlanta has a policy for—people can't wear any scented products. Or, you know what gets me? Hospitals. My husband has to have surgery. After I had my surgery—you're a hospital, why are you using scented products? They're bad for you. They don't get it either. When I had my knee replaced, I actually had to put a sign because the nurses wore perfume and cologne. We had to put a sign outside my door. You were not allowed in my room if you had it on because I would get sick. And they didn't get it.

KIM: Were they not receptive to that?

BELLE: No, they didn't get it. They didn't think—they didn't get it. They didn't understand it. I'm like, “You're a hospital. Why do you have air fresheners in your bathrooms? Why are you letting your nurses and your staff wear perfume and cologne when it can make your patients sick?” I said, “One of your nurses that had helped me had something on. I ended up getting sick.” They didn't get it. I said, “You're a hospital.” That's why my pulmonologist said, “Don't go to the hospital because you'll get sicker.” Do my breathing treatment at home, and I do. I'll sit there with my little mask. I have my albuterol and—I haven't done it lately. The only nice thing about this lockdown is I haven't gotten sick that often. It sucks because—to find stuff to do. But, yes, it's nice because I'm not getting sick as I usually do. I did find out that California has different laws than other states. That's why that attorney in San Fran(cisco) can do their lawsuit because your laws are different in California. I hope your study does help bring awareness. I think you're the first ones that are doing a study in the United States besides Anne, who does all kinds of stuff—because nobody else cares. Like I said, if I could help one person a month find out that that's what's making them sick, then I did, at least, something. That's my theory.

KIM: Yes.

[01:38:39]

BELLE: Nobody helped me, but if I at least can help somebody else. Well, I hope I answered all your questions, because we've been on here for a long time.

KIM: Yes, definitely. Everything you said was so helpful. It's great to get this big picture of everything that's going on, and especially because you do a lot of advocating.

BELLE: Yes, or if you have any follow ups, just drop me an email. We can talk again.

KIM: Yes, of course.

(INTERRUPTION)

BELLE: I also joined the Asthma and Allergy Foundation of America. It's called AAFA. I found them just recently, in October, November, and I joined. They have a community where people post posts. I posted something about fragrances and stuff like that. I got a whole bunch of reactions. They usually only let it up for like a couple weeks, but they said, because I was getting so many replies to mine, they let mine up for a while. Well, somebody had said something about masks, where they feel bad when they have to wear masks because people were looking at them strangely. I told them what I did—I thought of this (nose plug)—and they were like, “That was awesome.” So, yes, the AAFA. They come out with—I get texts and emails from them regarding asthma issues and stuff like that. Or, if somebody, they—and then I go look at different people's posts, and I try to help those people if they have questions. I just joined that, AAFA. They send out stuff all the time because of the asthma. I just got my inhalers, too, for free, from—because the insurance I have, I don't have prescription coverage, so for a while I wasn't using an inhaler because it was so expensive.

I found out that some of the companies have programs that actually give you your inhalers for free. I just qualified for that, so I just got my inhalers back. I had some of the rescue ones, still, because they hadn't expired. But my regular one I use every day, I couldn't use it because I wasn't paying \$175 for an inhaler. Yes, now I'm getting them for free, which is nice. It was nice to find that out. I found out from the AAFA that there's other people—so if you're talking to anybody else who has asthma and they can't afford their inhalers, they need to look at the manufacturers because some of the manufacturers give them out for free. Or, have them go on the AAFA website if they have asthma or allergies because they have a list of all the companies that give discounts on drugs and stuff because a lot of people can't afford medications, so they stop taking them. I was one of them because I wasn't going to spend \$175. I'll spend up to fifty, sixty, but—one of my eye drops is forty-five bucks. Prescriptions are so expensive but—yes, I'm glad you guys are doing this. So, please tell your professor, “Thank you!” when you see her or talk to her. I was hoping that somebody in the United States would do something, and at least UCLA is a big school. It's a big name school, you know what I mean? Hopefully it will bring something out of it. It will make people more aware of it. But, like I said, too, when you get a chance, go to Anne's website. There's all kinds of cool studies she's done. I mean, they're bouncing around the same—There's stuff, people with autism, they found out scented products bother people with autism. Asthma, allergies, and then just baby products. She did one on baby

products and how bad baby products are because they have scents in them. Yes, love her. Well, I hope I was able to help you.

[01:43:44]

KIM: Of course. Yes. It was great talking to you. I got so much information and I learned so much from you.

BELLE: Oh, good. I'm glad. Like I said, I'm just trying to make people aware. Like I said, if I can get one person to change or help. So, you'll now pass it on to other people. That's all I'm trying to do because nobody wanted to help me. I'm trying to help other people try to feel better. Even if I do go to restaurants and they don't have an air freshener in their bathroom, I make sure I go and tell the manager, "Thank you." That I will come back to their restaurant because they don't have one. There are a couple restaurants that we frequent now because they don't have an air freshener. Or, a manager said, "Well, we'll take it out." I try to go back to those places that are helping me, or I tell the people, "Thank you for not having it." Just to tell them "Hey, you've got my business now because you don't have one in your bathroom." I don't know if they use air fresheners in California, but I call—

KIM: Yes, there are.

BELLE: —the South the air freshener capital of the world, because we got (tourist attraction) and (tourist attraction), so we—because you guys got (the company Belle previously worked for), if you walk into any of their hotels, any hotel, they have air fresheners.

(INTERRUPTION)

[01:45:02]

BELLE: Well, I'll let you go. It was nice talking to you. Nice meeting you. I'm glad we sort of did it in-person like this. If you have any more questions, just drop me an email. I did give the name—I didn't give your email address, but the main one, to the girl I talked to in Minnesota. I'm going to talk to her on Monday. I'm going to tell her if she wants to participate, to contact you. I just emailed it to her yesterday. If someone from Minnesota contacts you, I'm the one that gave her—the main one, the one I originally emailed. I told her they might take a little bit to get back to you because they're on lockdown too. This was interesting. Like I said, I'm glad someone's finally doing something. Like I said, I call MCS the new gluten. That's how I explain it to people. It's the new gluten. You know how people didn't know about gluten? Now people are going to know about this.

[01:48:35] (End of April 2, 2020 interview.)