

## Oral History with Megan LeGresley

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Interview with Megan LeGresley

SESSION 1 (9/18/2019)

[00:00:00]

APOLLONI: This is Alexandra Apolloni. I'm here at the UCLA Center for the Study of Women. It is September 18, 2019, and it is 1:10pm. I'm here with Megan LeGresley. We are doing an oral history interview for the Oral Histories of Environmental Illness project. How are you today, Megan?

LEGRESLEY: I am well.

APOLLONI: Good. Why don't we start off with a basic introduction? Can you tell me when and where you were born?

LEGRESLEY: I was born on January 18, 1997, in Bellevue, Washington, which is very close to Seattle. I grew up not too far from there, in a town called Redmond.

APOLLONI: Can you tell me a little bit about your parents and your family background?

LEGRESLEY: My dad is English and German. His mom came over after World War II, and his dad had been stationed in Berlin when they met. My mom's dad came from Iceland when he was nineteen or twenty years old. My mom's mom is from a very small town in eastern Washington called Endicott.

APOLLONI: Do you have any brothers or sisters? What was the family situation growing up?

LEGRESLEY: I have one younger brother. He is in college, now, so he's not technically very young, even though I still think of him like that. We lived with my parents, my brother, and my dog. It was a suburban environment—pretty quiet, but still close enough to a city if we wanted to go to football games or soccer games. All that was available. All schools were within walking distance, which is something I think I took for granted back then—how we walked and biked to school. All of our friends were around to hang out with all the time.

APOLLONI: What was your home like, growing up? Can you walk me through your house?

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LEGRESLEY: It was smaller than most of my friends' homes. My parents chose to live closer to the schools and to the town, rather than out on more land. That was the experience they wanted us to have—growing up around people. We had a two-car garage, little laundry room, guest bathroom downstairs, kitchen. We did a big remodel of the kitchen when I was in about eighth through tenth grade, so it looked very different from when I was growing up to when I eventually left for college. It's still one of those places where, if I had my eyes closed, I could walk through the entire house, because that's where I lived starting at age six and all the way through eighteen. So, family room, living room, and dining room—which we used only during holidays. We were usually the go-to house for Thanksgiving and Christmas, and enough of my

relatives lived close—grandparents and cousins—that we could see them relatively frequently. Upstairs, we'd have the office, my room, my brother's room, a small bathroom, and then my parents' room.

APOLLONI: Do you remember any distinctive smells in your childhood home?

LEGRESLEY: Definitely specific days of the year—mostly holidays. We had traditions that we would do more or less every year. If it was Christmas time, we either had a fake tree or a real tree. If it was fake, we'd still have the pine candles, so it would still smell like Christmas. My mom was big on candles. We always tease her, now, because she has a big lineup of glassybabies, and she's always, like, "I don't have that many!" And, we're, like, "Yes, you do!" I think it's comforting for her, after dinner—she lights all the candles so the smell of food dissipates.

Whenever I'm there, it always seems bright, whether it's daytime or nighttime. There's this little mirror in the entryway and she'll do a different display—depending on the time of year—with colors and lights. So, it always seems very put together and very comfortable. Even the smell of sports practice—I remember, in the laundry room, my mom would always go, "Take your shoes outside!" But the turf was already everywhere.

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APOLLONI: You said it seemed bright—was that from the candles that were there?

LEGRESLEY: Yes, it was from the candles and the lights. She'd have little string lights up, with pumpkin faces or something if it was Halloween.

APOLLONI: It sounds like tradition was really important in your household. Would you say that's true? It's about celebrating these holidays together?

LEGRESLEY: Yes. Celebrating together was important. I wouldn't say it was traditional in the sense that it's conservative—we never went to church. But, it was important, like, "Okay, we're going to have everyone over." We just expected that—you know, it's Christmas break—we are going to pick out a tree and then the cousins are going to come over.

APOLLONI: Do you remember what kinds of products your family was using? What did your mom or your dad use when they would clean?

LEGRESLEY: I remember, very distinctly, Bon Ami, because, for a very long time, I couldn't figure out what this product was. It was in this bottle that looked like a gigantic cheese shaker. I don't remember smelling it when I was young. I remember, every two weeks, my mom and dad would clean the bathrooms, and every night we would use the Swiffer. My mom would usually do it, but if she was gone, then my dad or one of us would do it. Dish soap—it was the one with the duck on it, the blue container.

APOLLONI: Okay, yes.

LEGRESLEY: That's always how I knew what it was. I did think, "Okay, I have to make sure it bubbles," when I was learning how to wash the dishes. I was, like, "That means there's enough

soap in here.” Other than that, I don't remember my mom wearing a lot of perfumes until I was older. So, there wasn't a ton of smells, when I was growing up, that I linked, specifically, to chemicals or products.

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APOLLONI: Did anyone smoke in your house?

LEGRESLEY: No smoking.

APOLLONI: Did either of your parents work? What did your parents do for work?

LEGRESLEY: Both of them got degrees in business and accounting. They both worked until my brother was born, which was when my mom started to stay home with us. My dad kept working as a CFO (Chief Financial Officer), COO (Chief Operating Officer), usually for smaller tech companies that were relatively close. But, he would change jobs every couple of years, especially after he started to come in and help re-organize and take a company public, then move on. I remember, distinctly, that everyone worked for Microsoft where I was from, and my dad didn't. So everyone asked, "Where does he work? Does he even have a job?" "Yes, he does." So, finally, when he got to ring the bell on the Stock Exchange, I felt like I could describe his job in a way that people understood.

APOLLONI: That's very funny. It sounds like neither of your parents were working in industries where they would have been exposed to chemicals or anything like that?

LEGRESLEY: No. I don't think so.

[00:07:09]

APOLLONI: Did you show any signs of illness when you were growing up?

LEGRESLEY: I had ear infections frequently, especially when I was in daycare. Other than that, not until I was about fourteen did I notice anything else. I played sports a lot, and whatever my parents made, I could eat. We tried to eat healthy. The one rule my mom said was—no high fructose corn syrup. She said that she read that it's bad. I asked her, "What about my Ritz crackers?" She said, No. At that point, it just seemed kind of mean. We made pastas for dinner and frozen corn and it was fine.

APOLLONI: Would you describe your family as being very health conscious?

LEGRESLEY: Yes. My dad was a cross country and track runner growing up. They would both work out in the mornings. My mom would go to the gym when we were at school, and my dad would run on weekends. I just remember they would work in the yard a lot. They always did their own yard work and all their own housework, so they were always just moving. It was normal, you know, if you wanted to go for a walk or to the gym.

APOLLONI: Right. You said that, when you were about fourteen, something started to happen. Can you talk a bit about that?

LEGRESLEY: The first thing I noticed was that I couldn't really run anymore. That was a big deal because I was pretty good at track, and I had just joined the cross-country team for the high school. They thought, Maybe it's asthma—you can't breathe too well. At the same time, I was getting more fatigued, in general. But, they said, “Okay, your body is changing; maybe you're also iron-deficient.” I went through basic diagnoses that kids tended to get around my age.

It was at fourteen, fifteen years old, when I moved to the high school building, I noticed that the air just didn't feel quite right when I walked in. I couldn't pinpoint it. I was like, "Why do I get a headache when I walk into this building? Why do I feel like I'm going to pass out?" I'd get really lethargic, and it became a little bit more difficult to do my work. It wasn't so much in the home. It was when I would go into the building—where there was a lot of people, maybe—that I started to feel off.

[00:09:23]

APOLLONI: And, running was a big part of your life, at this point?

LEGRESLEY: It was. My dad got me into running in sixth, seventh grade. He said, “You should try out for the middle school track team.” I had always played soccer, softball, basketball, so sports wasn't a new thing. I said, “That's way too far. I'm only going to run the eight hundred meters—two laps!” In the first meet, my coach convinced me to do the mile, which was four laps. I ran it, and I was pretty good. So, I thought, "Okay, maybe this is all right." My dad would go out with me on the weekends and run all the hills. I just wanted to walk the hills. I remember he said, “It's going to happen.” Then I got to a point where I would run past him, and he said, "You have to turn around for me sometimes." It was cute.

APOLLONI: When you started having trouble running, did you talk to your coach or with your parents, or both?

LEGRESLEY: Both; I think we were all confused. Of course, I just thought, “Maybe I'm not trying hard enough.” In my mind, that was what it always was—You just have to push through it. Be strong. That went on for all of high school, basically, until senior year, when I was like, Maybe I'm just not tough anymore. Even though, when I said it to myself, I knew it didn't really make sense. It was the only explanation that I could really think of. My mom was the first one to really believe me, because I just kept saying, “It is not in my head. They keep telling me it's something up here.” I went to a psychologist, and she gave me a workbook and that stressed me out way more. It wasn't helping.

APOLLONI: What was the first point when you decided to see a doctor about this? Was this still around the time when you were fourteen?

LEGRESLEY: I would say fifteen, sixteen. I started to study from home at sixteen.

APOLLONI: Okay.

[00:11:11]

LEGRESLEY: I really didn't know if it was only in that building, and I thought something else was going on, too. What I did know was that, when I go into this high school, I'd basically pass out. So I thought, "This is one thing I can figure out." Even though I'd been to the allergist and infectious disease doctors, and they all just said, "We don't know, you look just fine." We started to look for other schools, thinking that maybe it's just something in this building. I was able to find a school where I was not so bad, so that's where I went to my second high school. But then, by eighteen or nineteen, it started to be basically any room I go into—wherever someone sprays a perfume or where I could tell they've been cleaning—I'd get the same sensations, but worse. I get really angry, really tired, and just tense.

APOLLONI: Did you tell your teachers that this was going on? Did you tell your friends?

LEGRESLEY: My friends knew that I couldn't breathe. Most of my friends were on the cross-country team, so they could obviously see something wasn't right. I eventually made a Facebook post about it, asking if anyone else felt this way. This is in my first high school, and some of the other girls did—girls I knew since kindergarten! They said, "I go home and I nap the whole day."

So, we went and tried talked to the principal about it. We were like, "Could you test the air?" We hadn't linked it to the chemicals, but we knew it was something. The school did some air tests. Eventually, they found chemicals leaching out of sinks in the chemistry room. Years later, my chemistry teacher, eventually, came to me and told me what they actually found. So, that obviously was not helping. The school was built on swamp land, but I'm also sure that there was something they were using that wasn't going so well.

At sixteen, I noticed that this was all women, because it was only girls who responded to me. They were on the cross-country team, and I could see whenever someone wasn't feeling well—I could start to see it on their faces. It was only the girl's team.

APOLLONI: That's interesting. Did you have male friends who knew about this?

LEGRESLEY: Yes.

APOLLONI: What was their reaction? Did they believe you?

[00:13:32]

LEGRESLEY: I think they did, just because I'd been running with them for years. I went to school with them every day, so they knew something wasn't right. I think they believed me; I don't know exactly what was going through their heads. I never really asked them. I do know that they were very supportive of us. When the girl's team had a really bad race, even when our coach had no idea what to do, they came and brought us chocolates, and they were like, "It's okay!"

APOLLONI: Do you remember the first doctor that you saw and talked to about this?

LEGRESLEY: The first doctor who diagnosed me with something that made sense diagnosed me with Lyme. She was in Seattle. I don't remember how we found her, but it was definitely way

down the line—we'd seen so many people already. She was the first one to test for certain viruses and bacteria that other people tended to think didn't apply.

APOLLONI: Right.

LEGRESLEY: She said, "We don't know how to treat this." But, that was the first time I felt like I had a diagnosis from someone who said, "You're not crazy."

APOLLONI: So, you'd seen lots of doctors up to that point—what kinds of things were they telling you?

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LEGRESLEY: "It's in your head" was the main one, or, "All your tests look normal, for the most part." Not a whole lot of answers. They'd say, "Your iron is too low," then, "Your iron is too high," and then, "Have an inhaler." That didn't really work.

The school said, "The air is fine." That was before I could read lab reports very well or had done my own research. I started to not remember—those chunks of my life where I felt the worst, I don't remember. Whether that was the brain damage from what was going on, or me trying to not remember—it's a combination.

APOLLONI: You said that you got sent to psychologists about this. How did that happen? How did you end up going down that route?

LEGRESLEY: I don't remember. For a while, I didn't know if it was linked. My mom was worried that I had an eating disorder. Now, I know that it can be linked to Lyme, and also just growing up as a girl and as an athlete. But, that wasn't making me feel bad. It was making it worse when I had to go to a doctor, and they would say, "Oh, your arm is too small." I wondered what that meant about me—why are they forcing me to eat ice cream when I don't want to, and I feel fine? I was just a thirteen, fourteen year-old girl—I'll be okay.

APOLLONI: As a teenager experiencing all of this, it must have been really tough to be in the position where people weren't believing you when something is wrong. Who were your sources of support at this point?

LEGRESLEY: Still the team, but I was known for being really quiet—especially at fourteen. I started to talk more when I was fifteen or sixteen because I was more comfortable with the people that I met. But I never talked about how it felt, because it took me years to even try to put it into words—to try to figure out what was going on. There were times that I had to just go home from practice, and I was literally crawling up the stairs. That was when my mom said, "Okay, we're going to figure this out, because this is not normal, and I can see what's happening."

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APOLLONI: You went to a different high school eventually; did that mean leaving the team?

LEGRESLEY: Yes.

APOLLONI: Were things better at the new high school in terms of how you were feeling?

LEGRESLEY: Yes, to an extent. I could go to class, and I could do well enough on all my tests that I felt like it wasn't hindering my schoolwork too much. At the time, I thought, "Well, that's all I have left." I had to apply for schools soon, and all my recruiting offers for running were long gone. I decided that I at least wanted to be able to keep one thing. So, that was my focus—I just wanted to get to a place where I can study and maybe figure this out.

APOLLONI: You mentioned that some of the health effects you were experiencing included fatigue, stress, and anger. Were there other notable symptoms that you were experiencing?

LEGRESLEY: I was really, really hungry all the time. I don't know what kind of hormonal mess I was getting into, but my progesterone and everything had tanked. I was basically a postmenopausal woman, from the hormone levels, and those haven't changed, yet. I'm still working on things like that. I was just hungry and tired. I just wanted to sit, eat food, and not move, and that is not me at all. I couldn't really read the tests—I was reading it, but nothing was processing.

APOLLONI: Do you mean tests at school?

LEGRESLEY: Yes, especially in my first school. I remember this calculus test, super specifically—. I was like, "I don't think this is hard, but I have no idea what it is asking me." When I was running, my legs would just stop moving—I could feel it coming. People have probably heard me say, "No," because I could feel it. It was like a sudden stop. I didn't know what was going on and thought, "Is this like a neurological thing? What is going on?"

APOLLONI: Some people we've talked to have described knowing what triggers there are that cause their symptoms. Were there specific triggers for you, or would you go into a building and just know that there's something that makes you feel unwell? Were there specific instances where something that made you think, "Oh, it's that"?

[00:19:46]

LEGRESLEY: Starting three years ago, when it was consistently pretty bad, buses are the worst for me. I don't know if it's the fumes, or something they use to clean it or filter the air. But, if I take a bus, I have to have someone waiting for me on the other side, because I will pass out mid-ride.

APOLLONI: Oh my god!

LEGRESLEY: Classrooms are not good. Usually rooms have less filtration, and the most cleaning products and perfumes. My mom knows she cannot use perfume in our house. Laundry detergents—I can't sleep in sheets with fragrance on them anymore. Those are the main ones. I know when I walk into a place.

There is one hotel that I sometimes have to go to before finals, and my parents know this. They said, "If you have to get through your test, go here!" It's the one place where—I don't know what it is. I know they clean it, and there's a very distinct scent they use, but I'm fine.



APOLLONI: That's interesting. Which hotel is it?

LEGRESLEY: J.W. Marriott Santa Monica.

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APOLLONI: Good to know, because sometimes we have guests who we need to accommodate.

LEGRESLEY: It's super expensive, and I feel really bad about it. But when I walk in, I feel almost normal. I don't have to eat all the time, and I can sleep normally. I can get up in the morning, which is huge.

APOLLONI: So interesting. I wonder what's going on there. So, you get through high school, and now you're at UCLA. What was the process of transitioning from high school to college like?

LEGRESLEY: In the spring of my senior year, I got really bad food poisoning. I had just started to feel better and gone through a huge Lyme treatment, which had helped everything a little bit. I was on really strong anti-parasite meds that summer.

When I came to UCLA, I didn't initially have too many chemical problems. I used perfume that I know now I will never spray on myself again. I could do schoolwork okay. I was still hungry all the time; it was hard for me to run. But, it wasn't too bad. I could handle things okay. That spring, I had really bad appendicitis, and I had my appendix removed. After that surgery, it was back to what it had been in high school. I don't know if it happened because I had an appendectomy—even though I had to have it out—or if it was a combination of things that caused both.

Working that summer meant taking the bus again—which was a struggle. I thought, “Maybe being home, I'll start to feel better,” but I didn't, really. When I came back to UCLA and moved to a new dorm, that was when I basically crashed for good.

APOLLONI: You mentioned that you had the Lyme diagnosis while you were in high school and had been through treatment for that. When you first got to UCLA, how was it being in classes? Were you doing okay?

[00:22:58]

LEGRESLEY: I was doing really well. I knew our high schools were pretty hard, where I'm from. It's funny, because my brother said the exact same thing a few weeks ago. He graduated from my first high school. He said, “No, everyone is so stressed, they can't handle this. Compared to high school, this is really easy.” I told him, “Before I got really sick, the schoolwork was not a problem at all.”

APOLLONI: Did schoolwork start becoming a problem?

LEGRESLEY: Yes. My sophomore year, I would get three Ds on my finals, one after another. Usually, my head would bob in the middle of tests. I tried to get on the cross-country team here,

and it didn't end up working out. That was the last thing that I was really holding on to. That probably didn't help, even though I was like, “Okay, I can do other things.”

I did a lot more extracurricular activities, which was fine, but the schoolwork got really hard. I moved to an apartment, thinking maybe it's just the dorm that I don't feel good in. It didn't help a ton, but it helped a little bit, for sure. I was still using conventional cleaning products; I hadn't really linked it to that, yet. I thought, “Maybe there's mold in the dorms”—which there could have been.

APOLLONI: It's possible. Did you talk to any of your professors or reach out to any anyone on campus for support?

LEGRESLEY: Never did. I was on the gluten-free pantry list through the Center—I don't remember what it was called. Now, it's called—

APOLLONI: The Center for Accessible Education?

LEGRESLEY: Accessible education—yes, that's it! That was my only kind of communication with them. I never talked to any professors.

[00:24:38]

APOLLONI: What prevented you from talking to professors?

LEGRESLEY: I'm stubborn. Didn't want special treatment. I felt like other people were worse than me. But, probably the main reason was that a MD doctor wouldn't be able to give a diagnosis they recognized.

APOLLONI: Yeah, that's hard. That must have contributed to such a—

LEGRESLEY: Even if it could have been Lyme, they wouldn't have known, and that was the closest diagnosis I could give.

APOLLONI: Were you getting medical support, at this point?

LEGRESLEY: I was. I had a good naturopath back in Seattle that I would see. She was trying, and she's great, but, I was too bad—she would give me things, but it wasn't enough. But, I think that's still the case, even though, within the past year, since I took a year off school, I started going to, basically, the best place in the world for Lyme and any related illness. Lots of chemical sensitivities, Babesia, Bartonella, parasites, mold, heavy metals, chemicals—they dealt with it all. That's when they said, “Your chemical load in your body is really, really high.”

That's when I wanted to use all-natural products. I had to get my family on it because I'm living at home. I redid all of my toiletries, and I haven't worn makeup in three years. I like it—it's made me branch out and understand what I need to do to keep myself as healthy as possible. But, up to that point, no one had linked it to anything that I was doing on a daily basis.

APOLLONI: How did you find those doctors or that clinic?

LEGRESLEY: A lot of research—it eventually popped up. It's led by a doctor who's really famous in the Lyme community, but we didn't know he had a place where he trained people to help patients. It ended up being close to my home.

APOLLONI: In Washington?

[00:26:44]

LEGRESLEY: Yes, it was in Washington. I wish that I knew about this place sooner. I'm still an active patient there. They're still trying to figure out what, exactly, is wrong. Even they haven't quite found it. Even though I've gotten rid of a lot of the infections, I'm still sensitive.

APOLLONI: I know that many people get Lyme from tick bites and that kind of thing. Were they able to draw a line for you to figure out what's wrong?

LEGRESLEY: I very likely got it from my mom, who got it from my dad, who got it from his mom. Probably back in Germany, because it's the European strain. I was able to go to Germany for treatment, and the treatment worked. They said it worked because I had the European version. But there are so many theories about how people in the US have it, especially now, so I don't tend to focus on where I got it. I just know that I have to be careful, because I can give it to other people if I still have it. The diagnostics aren't so good at this point, so I won't know for sure if it's gone. Right now, it's just being cautious.

APOLLONI: Right. Going back to UCLA, can you talk a little bit about your daily life as a student, having to be cautious of chemical exposure all of the time? What would be a typical day for you, going to classes? How would you navigate everything?

[00:28:07]

LEGRESLEY: I have a very hard time waking up in the morning. Usually, I get up as early as I can to make sure I get up in time for class. I shower twice a day, so I shower before going to class and when I come back, to try to keep my room as clean as possible. I definitely spend as little time in the buildings as possible. I go in just for class, and I'll walk right out after. I don't study in the library, too much. I haven't had a lot of problems with kids wearing perfumes. Every once in a while, someone will sit down with a really strong cologne, and I'm, like, "Oh no." I won't move, because I know, for one class, it'll probably be okay. But, if someone just sat down next to me, it's definitely something that I can feel—even if I can't smell it. I wish I could study more on campus. The resources are great—the libraries and other spots—but I tend to go back to my apartment, where it's quiet, I have my own products, and I have a lot of air filters going.

APOLLONI: Do you feel like you've missed out on anything at UCLA, because of this?

LEGRESLEY: In general, because of being sick, I missed out on a lot. I would have been on the sports teams, but that would have been at whatever school I was going to. That's a big one, just because I love having a team.

I don't have much of a social life. When I was going through rush my freshman year, I crashed in the middle and had to drop out. I haven't had a ton of friends—a few through my clubs, but you

don't tend to make your super closest friends through magazines or through scholarship clubs. It's lonely, and that's not something that really bothers me too much, knowing that I'm here to get my degree, and that I'm going to get a job and will have a community, eventually. But, you know—if I go on Facebook and see that the team went to camp, there's still some part of me that misses it and wishes I could have had that chance.

APOLLONI: What would you like to see in place for students that would prevent this kind of thing from happening?

LEGRESLEY: At one point, there was a research group for kids with chronic illness here. I went to it during my sophomore year. I saw one of the ads in the bathroom or something and was like, "You know, it's worth a shot!" That was really good, even though I was kind of hesitant about the idea of a support group. It was for helping you in terms of, "Do you feel differently about your situation?" There were other kids who were going to the school and having different, but sort of similar, challenges. It was just really nice to talk to them. You obviously know that everyone is going through something, but when they could talk about the same things that you were—that was helpful. They told me, "If you are ever on the bathroom floor and need to go to the ER, we're here." That was good to have.

[00:31:17]

APOLLONI: You had to take a year off of school. What was the circumstance that led to that? How did that end up coming about?

LEGRESLEY: I could barely pass tests, and I was miserable. I thought, "Maybe if I can take a year, I can get my health in order." I had a diagnosis, and we found a couple more doctors for me to try. I decided to just go for it, and I made some progress, for sure. During that time, I learned a lot and got health certifications and fitness stuff. I was like, "I'm going to research what it might take to be as healthy as I can." My whole family went on the Paleo diet, and I was helping them, in general, with natural-living things. I didn't want to force it on them, so I framed it as, "This is what I wish I would have known. And, also, you're also carriers of some of the things I am." I was especially worried about my brother, knowing he was going to start to go to college. I didn't want to have this happen to him. I told him, "These are the kinds of things you need to be prepared for. I'm not saying you're fragile. I just want you to be ready."

I went back because I wanted to see if I can get my degrees. It wasn't really any better. I was having a lot of trouble eating. Whatever I ate would cause an allergic reaction. It's called mast cell activation. My entire body just gets really puffy, and my heart beats really loudly. It's like you're allergic—but it doesn't matter what you eat. The same thing would happen when I drink water. My whole body was constantly on edge for anything that it has to deal with, whether that's a chemical or something I'm ingesting. It's like, "Nope"—it goes haywire. So, I end up fasting for weeks on end just to try to get through school. But, at the same point, when you don't have any energy, and you're taking classes, it's a no-win situation. I still came back and actually had to take another quarter off.

I ended up going to a place in Thailand, which is known for detox and for herbal medicines. I still take those when I'm here, and I think they help. It's not the cure, the be-all end-all, but it's another step that keeps me functioning well enough to hopefully get to school. That's my priority right now. I know I can't just focus on getting better, because I don't really have a clear trajectory of how that's going to happen. I've learned the ways to mitigate how bad I'm feeling and how to get my assignments done and my tests done—even if it's not as good as I could do. I have to be okay with that, right now.

APOLLONI: What took you to Thailand? How did you find that particular treatment spot?

[00:34:06]

LEGRESLEY: I have someone who does treatments down here who said, her friend who goes to Thailand on this retreat. I started to look into what she might go to, but found this other place, instead. It was a lot of people who said, "It didn't just help me with weight loss; I felt a lot better." These are really good reviews, so I thought, "We should try this one instead of the one she was recommending." By that time, I could read the labels on the products and know what sounded good. So my mom said, "Okay, well, I'll go with you. Maybe I'll lose a little weight." Like, okay, let's try that. It was something you do when you're at the end of the rope. I had no idea what else to try. I wouldn't ever have thought about going to Germany or Thailand, but when doctors here have no idea and insurance doesn't cover it, anyways—you know what?—we're going to try it.

APOLLONI: How was flying for you? It's a huge flight to get to Thailand.

LEGRESLEY: I actually feel amazing on airplanes.

APOLLONI: Wow.

LEGRESLEY: No one knows why. I get up in the air, and it's like this weight is lifted—I don't know if it's because it takes less air to breathe or something. Business class usually smells like a submarine. That smell—I don't know. I can't place the smell, but that was horrible. But back in coach, I'm actually fine. It was a long flight, and my legs were sore, but I don't tend to feel bad on airplanes.

APOLLONI: Wow. And, you also have been working while you're at school—is that true?

LEGRESLEY: Not this summer. But in the past, I would work.

APOLLONI: Did your illnesses affect work, at all?

[00:35:48]

LEGRESLEY: They would. I would try to hide it as much as I could, especially through January. I was working at JusticeCorps at the Santa Monica Courthouse. It's a very stressful environment, and there's a lot of work, but my illness had actually taught me the skills that I need to do well at work. So, I think it's kind of both—it might be hard to get out of bed and function at work, but when I'm there, I'm really good at what I'm doing.

APOLLONI: Were your colleagues at work aware of your health issues?

LEGRESLEY: They were. It tends to come up in conversation, like, if I lost something or if I can't explain something without mentioning, "By the way, I'm really sick." But, I was always like, "You know, it won't affect me being here." When they found out, they said, "You can go home if you need to." They did not know that if I used "I'm not feeling well, I have to go home" as an excuse, I would never come to work. I appreciate it, but I know how to come into work every day.

APOLLONI: Well, it sounds like you set a very high standard for yourself, as well.

LEGRESLEY: I think I've always been like that.

APOLLONI: Yeah.

LEGRESLEY: On the one hand, it's been hard to be sick, but on the other hand, it's maybe not as bad as I could have been, or it hasn't taken away as much as it could have.

[00:37:00]

APOLLONI: That's interesting. You've been super involved in clubs on campus. Do your colleagues at the clubs know about what's going on?

LEGRESLEY: Half and half. The people who I spend the most time with know. So, if we go out to dinner, I might say, "I'm not eating, but don't worry—it's totally fine." They might ask why, and so I have to briefly explain to them.

APOLLONI: Do you think of yourself as an activist on this issue?

LEGRESLEY: I do. I make a point of posting on Facebook every year, especially when it's Lyme (Disease) Awareness Month. If I'm feeling particularly bad, once every five months or something, I'd post something that says, "This is what I'm feeling," and also, "This is what we're working for."

Those are people who have known me since it started, so they know what's going on. I have some friends whom I've met specifically through treatments and through Lyme disease who really get it, but I want people to know because I feel like this could happen to anyone. I've done Medium posts about it, and I've put those on Facebook. I have a lot of writings that I've kept to myself for now. Eventually, I may share them, but not at this point.

But, I'm definitely not shy about it. If someone asked me what's wrong, and they actually want to know, I'll tell them exactly what I think. I actually raised money and ran a marathon this spring.

APOLLONI: Wow—oh, my God!

LEGRESLEY: Which wasn't my greatest idea, but I was running for Global Lyme Alliance. My dad did it with me because he had always wanted to run a marathon. He was worried and said, "You're fasting, and you haven't run in three years." I told him, "We're going to do it anyway."

[00:38:41]

APOLLONI: How did that come about? How did you end up deciding to do that?

LEGRESLEY: I wanted to do it for a while. I found Global Lyme Alliance a year and a half ago—maybe two years ago. The Hadids are really big into it, so I followed them and found it.

APOLLONI: Do you mean Gigi Hadid?

LEGRESLEY: Gigi and Bella, her mom, Yolanda, who wrote a book about her Lyme disease. I see people joining this team, (Conquer) Endurance, and run marathons to raise money—the big ones like New York City Marathon. I decided to do it but to start smaller. I reached out to them last fall—about a year ago—and asked if there was a team for the LA Marathon. They said, No, but there wasn't enough time to put together a team—"But we can get you and your dad shirts to run in to raise money!" And we did. I figured I had enough time to train and that it was going to be fine. Months went by, and I felt really bad, but I never thought about not doing it. I knew I was going to finish it because even if I had to walk, I can still technically finish within the time. My dad was, like, "This really isn't a good idea. Are you sure?" I said, "Dad, have you ever known me not to do something?" So, he said, "Okay." He's actually trained a little bit, and he could have run it way faster, but he decided to run it with me. We did the marathon half running, half walking. The running was fine, but of course my immune system was not happy.

APOLLONI: Oh, no!

LEGRESLEY: We finished, and I'm glad I did it. I think he's glad he did it. So, it was kind of cool. I still feel like I can make a difference.

APOLLONI: Yes. How much did you end up raising?

[00:40:18]

LEGRESLEY: I think we raised twenty-five hundred, or something—which is pretty good for people not knowing what we were raising money for.

APOLLONI: Yes, that's really good!

LEGRESLEY: It wasn't something that I could say, like, "Relay For Life," and they'd be like, "Oh, I know exactly what that is!"

APOLLONI: In the past few years, I noticed that people are more aware of Lyme disease. I'm wondering if you have noticed a shift in public awareness—both of Lyme disease and of chemical sensitivities? Have you seen any sort of changes?

LEGRESLEY: I'm trying to filter out being a part of more groups now. When you mention MCS (Multiple Chemical Sensitivity) mostly being middle-aged white women, I totally get that, because most of the Lyme pages are for the people who have time to do it.

But, I think so—there have been multiple books that have come out about people who have Lyme disease, or people who are researching Lyme disease. I think that's helping. There's

actually a congressional investigation into Lyme that's happening right now—I'm surprised they're even undertaking it. I feel like the fact that they're doing that is huge.

I don't know if I've seen as much on chemical sensitivity. I noticed, in general, people are talking about being sicker—they're not as afraid to speak out about not feeling perfect, anymore. In general, I think that will help.

I think there has been a turn in society's discussion—like, “Why are we sick all the time? We need to start taking basic steps.” Not just relying on the medical system once we are sick. I actually really appreciated Marianne Williamson in the democratic debates. She brought that up on stage when everyone was talking about healthcare. So, I think there is more awareness, in general. I would like to see more people talking about the chemical angle, though.

[00:42:09]

APOLLONI: Right, yeah. It sounds like you have had different levels of success in getting support from both medical professionals and from other people in your life. It also sounds like you don't reach out for support a lot because you are a very independent and self-sufficient person. Is that accurate?

LEGRESLEY: I would say I am very good at pushing people away when I don't want them to have to deal with it. That is true. I have some close friends who refuse to go away, who will always check in on me. One friend, in particular, says, “I don't want to show up at your parents' house someday for you to not be here anymore. Because that is going to be really awkward.” I was, like, “Thank you?” But I know they mean well.

I think my illness has driven a major rift with the extended family, even though there were other causes, as well. They don't get it at all, and they don't really try to, so that's been frustrating for my parents.

In general, there's no one I've talked who has been like, “I don't believe you,” just flat out.

APOLLONI: Yes.

LEGRESLEY: Everyone has some skepticism, but when they see that I really mean it, they tend to see what they can do. Traditional doctors have been the worst at that.

I just had to get my tonsils out because they were blocking my whole lymphatic system from draining. The doctors I went to would ask, “Do you have sleep apnea?” I would say, “No.” They'd say, “Then we're not taking them out, because there are risk factors. You might get sick.”

I said, “Okay, I already am sick.” I feel like, if I say I need something, and there's not just a naturopath, but an MD saying I need them out—not only should I be able to say, “This is what's best for my health,” but also, “Please listen to what another doctor is advising.” I'm not going to sue you, I promise—I will sign a form saying that—but I need them out.

[00:44:27]



APOLLONI: Do you have strategies for dealing with your illness—since this must make your day-to-day life much more stressful than the average person's day-to-day life? What do you do?

LEGRESLEY: I'm not great at it still. I feel the worst in the Westwood area, and I don't know why. It's about doing exactly everything you have to do. If you can do something else that you know is healthy behavior—you could go to the gym even for ten minutes, or go to bed at nine o'clock, or eat just salad today, then that's a win. I don't like having to lower my standards like that, but I know that, if I'm in a place where I don't feel great, but I'm here for a reason, then I have to do the little things to stay as healthy as I can. I'll delete my password for Netflix so I can't possibly get on. I just make my other decisions impossible so that I'm just going to have to study tonight.

APOLLONI: You mentioned that you noticed women around you who were also feeling sick in your high school. Do you think that gender has shaped your experience of your health issues at all?

LEGRESLEY: Yes, specifically with my hormones being very off. I had ovarian cysts that needed to be removed. I did try to date at one point, and that was basically impossible. I think it was harder because I was a girl performing that kind of role in the relationship. Most of the people I met on campus who are sick are also women. Most of us got sick around fourteen years old, when we hit puberty—which didn't seem to affect the guys as much. There didn't seem to be as much of a drastic shift in health. I don't know the extent to which gender is still impacting me, at the moment, but I will say my brother and my dad feel a lot better than me and even my mom.

APOLLONI: Beyond just having a female body and that affecting your health, have you found that being a young woman has shaped the way doctors or others interact with or approach you?

LEGRESLEY: I often bring my dad to appointments because people will listen to him more than they will to me. We've talked about that, and he'll go with me. I try to judge based on who I am going to see if I need him to come—sometimes it doesn't work, but I've noticed sometimes it gets us the tests that we need.

[00:47:23]

APOLLONI: That's interesting. That must be frustrating.

LEGRESLEY: It is, and I think he's equally frustrated by it. He said, “It's not me who's feeling this way, it's you!”

APOLLONI: What are your hopes, looking forward? What would you like to see in terms of scientific or medical research to address the issues that you've had to deal with as an individual?

LEGRESLEY: In general, I wish there was more of an emphasis on staying healthy and living in the ways that we did years ago. I don't want to say we want to go backwards or ignore some things that we have innovated or invented recently, but I think we need to recognize what we're doing to our environment isn't just things like climate change and big macro-level effects. I wish that people felt like we could talk about things like, “Why are we getting cancer at such a higher rate?” We're spending so much research on trying to fix these ailments once they've happened.

Every once in a while, people will say, “We need to start addressing illness before it happens.” But then we look at things like genetics, and, to me, it seems like we're ignoring the fact that kids are being born sicker and sicker. We need to focus what we introduced within the last seventy years—yes, for a purpose—maybe they made crops more productive. That's great, but how can we balance that with our needs as people?

We tend to think of ourselves as invincible. We don't want to think about the fact that some of the things that we're using are actually very bad and detrimental to us. We've gotten too used to life as easy or comfortable. It's hard to have specifics right now, because there's so much we need to do.

I think it's great that we're talking about universal health care. I've been very, very lucky to have the money to look into all this, but the traditional medical system isn't enough. If we're going to talk about universal healthcare, we need to also talk about things like naturopathic and Chinese medicine. There are things that we used for thousands of years that we can't just completely throw by the wayside now that we think we have better technology.

APOLLONI: Anything else that you would like to get on the record before we wrap up the interview?

[00:50:00]

LEGRESLEY: I don't think so.

APOLLONI: We'll stop things there for today. If you do decide that you have more to add, we can always do a follow-up, but I also want to be mindful of your time and your energy level.

LEGRESLEY: Thank you.

(End of September 18, 2019 interview).