

## Final Transcript Liza Levine

Hello, I'm Vanessa Corwin

And I'm Kathleen Kaan

VC: The Covid lockdown stopped everything in its tracks including some medical emergencies. Today's guest had a heart event that was affected by the pandemic. And I have to say that four years ago I myself had heart surgery and I met today's guest through WomenHeart, a national organization for women living with heart disease. Meet Liza Levine, from New York City. Liza, welcome and thank you so much for joining us today.

LL: Thank you for having me.

VC: So Liza, let's start by hearing your heart story. Now you were on vacation in California when you had to have heart surgery.

LL: Yes I was. I live in New York. And during Covid, in the fall, in November, I decided to come out to LA before Thanksgiving, really, to see some friends just stay for a few weeks and it was during that time that I had my heart event – I like the word “event,” that's a good one, it was quite an event. Covid was raging at that point in Los Angeles and I had just taken up pickle ball with my friends, I don't know if anybody knows what that is, everybody calls it tennis for older people and it's a lot of fun, and I remember playing a game and winning but being incredibly out of breath and thinking “oh, I got to do more cardio, I'm doing too much yoga, I need to fix this.” And then that proceeded to get worse. I was very out of breath, I had a sinus headache and I thought, this looks like Covid and I got tested and it came up negative. And it kept getting worse and worse and I got four negative tests. So what looked like Covid wasn't Covid. And I ended up in several urgent cares. Finally one of them sent me to the emergency room and I'll never forget because I just did not want to go to an emergency room and she said “Oh, don't worry; there's a whole non-Covid part of the hospital.” It was a zoo. It was horrible. I actually ended up getting Covid from being in that emergency room but during that emergency room they did take an X-ray and saw pleural effusion in my lungs which are not associated with Covid, but are associated with congestive heart failure.

VC: Now what exactly are pleural effusions?

LL: From my understanding it is a fluid in the lungs but it's different from pneumonia and Covid does not present that way. So everyone was pretty stumped and I remember the emergency room doctor asking me if I had been around any parakeets lately and I'm like, you've got to be kidding me? “No, it can't possibly be congestive heart failure, look at me.” And finally, someone said, “You should get an echocardiogram just to make sure.” And I went to UCLA for that but because I had tested positive for Covid at that point, even though I felt fine, except for the not being able to breathe part, when I walked into UCLA, the people at the desk were like, “Oh, you tested for Covid too recently, it hasn't been a full 15 days, or 14 days, we need to turn you away.”

And there was an older gentleman with a heavy Russian accent standing around and he goes, “You, I’m technician. You wear a mask. I wear a mask. I do your cardiogram.” And so he did. I’ve had a heart murmur since I was a child that no one ever heard as an adult but when he was looking at the screen, I was kind of joking around, saying, “Oh, do you hear my heart murmur?” And he said, “No, I see it.” And he turned the screen to show me and I could literally see my mitral valve, which I didn’t even know what it was then, it has these things called leaflets and they’re supposed to go up-down in an organized manner and they were just flying in the wind. My friend described it as you know those blow up things outside a car dealership? That’s what my heart valve was like and it’s not supposed to do that. So even I knew that it was pretty – that can’t be right. Of course the technician is not allowed to say anything but the doctor said, he sent me to the doctor immediately, walked next door, saw the doctor, the doctor looked at me and said, this should all be fixed immediately but I don’t know if I’ll be able to get you an operating room because of Covid. He’s like, OK, we should do this Tuesday, you know, five days later, he said, you know, fingers crossed, we’ll get you in. So, there I was in the middle of the pandemic with the hospital full of Covid patients and me having to have open heart surgery.

KK: Liza, this is an amazing story, and thank God for the technician, number one, to be kind and say “let’s give her the test.” Now you had to wait five days to get the operation.

LL: Yes.

KK: So where were you in California? Were you staying with friends, or...that had to be awful for you.

LL: It was awful. And honestly I, the only thing that got me through was a prescription for Ativan. I was lucky in a lot of ways. But the surgeon is a very well-known surgeon. He’s the number one heart transplant surgeon in the United States and I just said “look, I can’t believe I have to have this done”. I kept saying, “Can’t you do the one that Mick Jagger had where you go up my leg?” And he looked at me and went, “No!” And this was the day, by the way, of the Capitol riot. So on my phone I’m watching the downfall of America and I’m sitting in the office hearing that I have to have open heart surgery in five days if I’m lucky and the operating room is available. So he gave me a prescription for Ativan and that was the only thing that got me through the next five days.

VC: Now were you by yourself in California?

LL: No, at that point my husband was there. That’s right, my husband was there.

KK: Oh, and he stayed?

LL: But I really wasn’t thinking about him to tell you the truth.

KK: But isn’t it better to have someone like your husband or friends to support you during this time after the operation so once you had it, where did you go? Not back to the city, that’s for sure.

LL: No, no no no. We actually had a place to stay. But that was also stressful because it was a tiny house we hadn't planned on staying in for more than a few weeks so what was supposed to be a three week visit turned into a seven month stay.

VC: It was a seven month stay because you were not yet cleared to travel? I had a very similar operation to yours, I had the same condition, mitral valve prolapse with regurgitation so I had the same kind of surgery and I know that it took a while for me to get my energy, my strength back.

LL: Right, right, it definitely took me a while. I also had complications about – I don't remember, really, about six to eight weeks in, AFIB complications, and remember it was still Covid and people weren't vaccinated yet so nobody wanted me to get on a plane. And that was the other stressful thing. We didn't know in the beginning, remember when there was no vaccine and people were, like, fighting to get it, waiting in line and all that, well that was me. I even had to fudge, I totally lied and said that I was, well, I am an educator but I said that I was a certain kind of educator that they were letting go first. But none of my – I was asking all my doctors if I should get it and they're like, "maybe," no one knew what effect it would have on heart patient.

KK: That's very interesting. So even though the vaccine had started to come out they were not guaranteeing that this is something you should have?

LL: No, no. I had one cardiologist tell me to wait because he just wasn't sure and then one said "go ahead and get it", it was crazy.

KK: So you just decided, I'm doing it.

LL: I decided on doing it because everything was just so fearful. I was just so fearful of everything at that time, no, I decided to do it. And I'm glad I did, obviously. It was incredibly stressful.

VC: Oh, you absolutely did the right thing.

KK: No question. We hear that, and Vanessa could answer this too, I guess, because you both went through this—I've heard that it is not uncommon for people who have heart problems to become depressed after the operation, did that at all happen to you?

LL: Absolutely, absolutely. I was fine until the complications started. Totally fine. Because the actual surgery itself was apparently very successful for the kind of prolapse and fluttering in the breeze that I had, repair is only possible one percent of the time, and the surgeon was very clear to me from the beginning. He said, "I am going to try and repair but you could also end up having a replacement. So right out of surgery it was fine. Then at the six to eight week point when AFIB started and they couldn't figure out some other arrhythmias I was deeply depressed and what has been now characterized as PTSD which prior to this I didn't exactly mock but I didn't quite believe in it and now, oh, I so believe in it. I mean it's such a visceral reaction. And luckily I found

a therapist, someone I'd worked with before years ago for other things who were able to do that crazy rapid eye movement; do you know about this for PTSD?

VC: No, tell us about that.

LL: Oh, it's fascinating. It was developed; I forget the name of the person, for war veterans experiencing PTSD. I don't know how she discovered it, but you know in REM sleep your eyes move back and forth, right? And it's part of the process of the whole restoration part of that sleep. Well, it turns out that if you do those rapid eye movements while thinking of and channeling the part of the trauma that is triggering, you can lessen the effect that that trauma has. It is crazy. Again, I wasn't skeptical...

VC: Did that work for you?

LL: Totally.

KK: Did you feel like you're going back to those emotions and feelings-do you follow this by yourself?

LL: No, it's different. You do regular talk therapy first to identify the quote triggers, but you identify those things that make you upset. For me for example, right out of the hospital I had to use a walker. And this is someone who has run two marathons, right? So when I used to think about my days in the walker, I would just—inconsolable tears. I couldn't even say the word walker. So through the EM-rapid eye movement, whatever the acronym is—(VC REM) my therapist would tell me to picture the walker and then she would literally—we had to do it on Zoom, right? Can't even do therapy in person—she would move her finger back and forth that you follow with your eyes just literally, three or four sessions under ten minutes and it lessens the severity of your physical reaction to the image or the concept.

VC: That's amazing.

KK: That one is different.

LL: It is, it is.

VC: Now, when you got home, and obviously when your doctors said you were ready, did you do cardiac rehab?

LL: Yes. Honestly, that was the only thing that kept me going because I was stuck in LA, I was stuck in that house, a tiny house, it was the pandemic and cardiac rehab was actually a good 50-60 minutes from my house and LA traffic is notorious but I just remember being thrilled to be stuck in traffic! I'm getting out, I'm going somewhere, and it was great. And then the people are just so kind, and they're very knowledgeable, and it's just a very structured program, starting out on a treadmill, slow walking, on a bike, with a heart monitor the whole

time. The one I went to was affiliated with Cedars Sinai. They were really good, very professional. Also very collegial. Everyone there had been through it so that felt really good because I think it's super hard for people to understand who haven't been through it, just how big a heart event is in your life.

VC: I totally agree with you. And I have to say for me, I share your experience with cardiac rehab. That was the best thing that I did, because my surgery also, it was a repair and in my case they were able to do the minimally invasive approach and there were no complications. I did have, as they called it in the hospital, an unspecified episode of AFIB which, it was that one time and they put me on medication for it. But I got home, and I was recovering and doing all of this. Like you I was an active person, not a marathon runner.

LL: I didn't exactly run, I walked very fast, mostly.

VC: I would say in my case more like a gym rat. The idea of becoming active again—I really wanted to but I had a lot of fear. And the cardiac rehab, that helped me so much. It gave me so much confidence that I could work out hard. I'm not going to die. I mean that was the fear, irrational though it was.

LL: I don't think it was irrational. I don't think it was irrational at all.

KK: I mean from what I'm hearing it seems like it gave you back some control, and that control is very important.

VC: It's confidence, more than control. It's confidence that you can do what you like to do and you're going to be good.

KK: Did you continue the rehab when you got back to the city, when you got back to New York?

LL: I actually finished—I forget how many weeks the program is, but it's a limited program so I finished it in LA.

VC: It's like six weeks or eight weeks, or something like that.

LL: Yeah, it might be more. It might be more; it depends on how often you go.

VC: Yeah, because I went twice a week for, I don't know, maybe six weeks or eight weeks, something like that, I don't remember the exact...

LL: Right. I actually wanted to extend it. I had a conversation, like; can't I just pay to go? And they were like no, can't be done.

VC: Where I got my rehab that option did exist.

LL: Oh, really?

VC: Yeah. I was at Mount Sinai.

LL: Interesting.

KK: Now for women that are out there, you two guys connected through an organization called WomenHeart.

VC: Yes.

KK: Tell us a little bit about that.

VC: Well, WomenHeart is a national nonprofit organization and it helps women who are dealing with heart disease. And they have support groups, and that's how I met Liza because I'm in a support group and Liza came to our meeting, and so that's how we hooked up. It's great, it helped me a lot because it's just good to meet other people who have similar experiences to yours, maybe not exactly the same, but people maybe have similar experiences with medication and things like that. And I learned a lot, actually, from being in this group and it became important to me to be able to give back, to be able to help other people in the same way that people in my group were able to help me. So Liza, you're so great to have in our group.

LL: Thank you, no, I'm really happy to be here. I agree with everything you said, I think it's so important. I found another group first called Mended Heart which has been terrific. It all has to be over Zoom still, of course (VC: Yes). It is just so helpful to hear that other people have been through this. But I wanted to connect with, well I just wanted another one, I wanted more. I wanted more support so I started looking and I found the WomenHeart one which I think it's great that it's only women. I think it's a different point of view and I think you know, it was a pandemic. I'm not blaming anyone, but when people were looking at my pleural effusions in my lungs and saying it could be congestive heart failure and not sending me to a cardiologist, I'm thinking now, hmmm, if I were a man, I'm wondering if they would have immediately assumed, heart problem.

VC: That's a very valid question. And we know that there is a lot of bias in the health care community where women are not acknowledged or treated in the same way that men are when they present with symptoms that could be heart problems. So while there are a lot of providers out there who are sensitive to it there are still a lot of providers out there who are not, so I know that's one thing that WomenHeart tries to do is, they're into advocacy and advocating also for the research community – a lot of the heart research that we have today really has been done mostly with men and women are very underrepresented in the research community as well so that's another thing that WomenHeart does, they advocate for that. WomenHeart.org and you can find them on line, they have support groups all over the country so wherever you are you can find a group. And Liza, the other support group that you're in, tell us again?

LL: Mended Heart dot org.

VC: And then actually, one more thing. I'll mention another one, Adam Pic's Heart Valve Surgery Blog. This one obviously concerns heart valve patients and I found it most helpful before my surgery and during my recovery. I do still check in every now and then to give back. We'll put all these resources up on our website. And what about now that we're facing this new and very deadly variant. Are you experiencing other challenges because of this?

LL: It has been insane. I work at a school where all the adults are required to be vaccinated and we just, today and three days ago had two fully vaccinated teachers test positive. So it's just crazy and I mean, you know, knock on wood, I'm sure they're going to be fine. One has no symptoms at all and the other has like flu-like symptoms, but I wear a mask all day long, all day long, probably like 9-10 hours but I'm also not willing to sit in my apartment all day, again, I just can't, cannot do it so I think at this point everyone just has to make their own personal choice, like how much am I going to go out and live my life carefully until I hear otherwise because right now from what I personally am seeing is a lot of breakthrough cases but people not getting super sick. And of course there's always a worry that Covid affects major organs differently. There was talk early on about how it might affect the heart. And again, I can't sit in my apartment, you know. So I put on my mask and I go to work every day. I enjoy my job, I work with both kids and teachers but it does give one pause, doesn't it?

VC: Indeed, and you're so right about that. You do have to live your life and that's probably the best advice that my cardiologist gave me. She said, "go out and live your life" and so that's obviously what you're doing, Lisa

VC: So, thank you so much for sharing your experiences with us, Liza. This was awesome.

KK: An incredible story and experience that you've gone through.

VC: Oh, and one more thing, do you have any advice to other people out there?

LL: Yes. If you have had to have this happen to you or someone you love, some clichés are so true, right? Time heals all wounds. It just takes time. And when you're in the thick of it, six months seems like forever but honestly at the six month mark I woke up and went, "Oh, I'm kind of a normal human again, and it really does get better, it really does."

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