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Stephen Calabria: From the Mount Sinai Health System in New York City, this is Road to Resilience, a podcast about facing adversity. I'm your host, Stephen Calabria, Mount Sinai's Director of Podcasting.

This installment features a special edition of our show, in honor of October being Pregnancy and Infant Loss Awareness Month.

Joanne Stone, MD,MS, is the system chair of the Raquel and Jamie Galinski Department of Obstetrics, Gynecology and Reproductive Sciences at the Icahn School of Medicine at Mount Sinai.

She's also the director of the Mount Sinai Rainbow Clinic, which offers enhanced prenatal care to patients. Following stillbirth on this episode, Dr. Stone interviews one of those patients, Stephanie Lee.

While receiving treatment at other medical institutions during and immediately after her pregnancy, Stephanie experienced the loss of her baby Elodie at roughly eight months. In the aftermath, she came to the Mount Sinai Rainbow Clinic for treatment and guidance, eventually becoming a mentor to those who have experienced similar loss.

Stephanie's struggle, [00:01:00] pain and resurgence serves as a model for those who must soldier on through the most devastating of circumstances. We're honored to welcome Stephanie Lee and Dr. Joanne Stone to the show.

Joanne Stone: Stephanie, welcome. So good to see you.

Stephanie Lee: Good to see you.

Joanne Stone: So we go back a long way just back in 2022 was, I think when we first had our first conversation. So tell me a little bit about your life before you became pregnant the first time with Elodie.

Stephanie Lee: Sure. Up until then I'd been a nurse here in New York City. I've practiced in Maryland, Baltimore, as well. And I was working as a critical care nurse. Currently I do administration, but my life was pretty simple.

It was just me and my husband. We got married pretty early in life. I was 24.

Joanne Stone: Oh, you were young.

Stephanie Lee: I was young and so we hadn't even, I think I was, before I was pregnant, we had been married almost eight years. And so [00:02:00] we were double income, no children, kind of family, and, or no kids, a dink as many will refer us to as.

And we just grew up together working as a nurse, enjoy coffee and dining at cool places, traveling around the world until we finally decided to, quote unquote settle down.

Joanne Stone: Sometimes you just have to pick the, I was married probably seven or eight years before my first as well, you get to a point where you're like, okay, if you're gonna do it.

Is there ever a right time? I don't, you know,

Stephanie Lee: I don't think there's ever a right time. I saw a lot of my girlfriends who were career women, married, and I saw that, the whole like fertility process wasn't as clear cut as I think sometimes the world likes to make you think it is. And I'd seen a lot of up and downs.

I knew that different risk factors increased as you got older. And so I didn't want to go past a certain age and then start only to realize that it wasn't gonna have immediately. And so I think with that in mind, [00:03:00] we finally got to a place where we felt as settled as we could.

And then we're like why don't we start trying quote unquote and we can navigate from there? And so I think that's how we started our journey to get pregnant and have a family.

Joanne Stone: Yeah. It's so nice to have that time together beforehand, especially when you're so young. So tell me in the first pregnancy with Elodie, tell me what do you think were your expectations and hopes and thoughts about that pregnancy?

Stephanie Lee: By training, I'm a surgical ICU nurse, and so I think my exposure to pregnancy and being a healthcare worker, and being an ICU ER nurse, I think my head naturally always goes to the worst case scenario.

All the cases I had always seen were more around bad things happen to mom, not so much the child. I don't think that ever really crossed my mind. And for

the most part, most of the moms I know things, bad things can happen. But, your mind just goes, oh. Here's what's next.

One [00:04:00] of the things I beat myself up about, but I guess at the time you don't realize is, you think about a lot of material stuff. Which stroller do I want? Like, how am I gonna change your house to accommodate this new child?

Can we still go out to eat? It's like lifestyle changes. Oh, that's a really cool blanket. I want that, or what's the next baby carrier that would work best for us? What's stylish and or what diaper bag, that was like the big thing for us.

What diaper bag I wanted and nesting. What do we want to eat before we go into the hospital? What's that gonna look like? And then up until that point, like we had some concerns about Elodie at the time.

And trying to think, okay, so what's our mitigating like plan? What's plan A, B, C, D, 'cause my husband's a big planner and so am I to a degree. And, what are our contingency plans? Who can we lean on? What are we gonna do at this kind of scenario?

Joanne Stone: Were there any moments with Ellie towards the end, I guess, that you felt like maybe something was off?[00:05:00]

Stephanie Lee: Yeah. There was a point, it was at my baby shower actually. My best friend, my GYN best friend, she saw me, she was actually pregnant.

She and I were pregnant together. Her daughter was due just shortly after Ellie was supposed to be due. And she looked at me and she said, Steph, you're really taught. I had always carried really large. But she was like, this is really tight.

And I had brought it up previously, but I was constantly told that people carry differently. People carry large, some people carry soft, like smaller. So I didn't think much of it until she was like, you should go ask about an AFI.

And then my husband and I naturally go, what's an AFI? We had no idea. And she goes, ask for an amniotic fluid index, like a intern can do it. It's not a big deal, Steph, but ask. And I, really tight.

That's what started this like downward spiraling of just, oh my God, something could be bad. So [00:06:00] that happened probably around 28, 29 weeks. And from that point on, I was referred to a maternal fetal medicine specialist, a high

risk doctor, and they started tracking me and each time my test came back inconclusive, but I was told everything was okay.

I was told that there might be something physiologically wrong with my baby. That there, the tests didn't show that there was anything wrong with me, aside from my high amniotic fluid levels. And really the last couple weeks was us preparing for a neonatal ICU stay.

And so that's where I was talking about like having contingency plans. Death was never really something that was ever on the table. It was just, she would need surgery, but she needed to grow.

We actually didn't even know she was small. My daughter had an inner ear growth restriction that we didn't even know until after she was born. We only found out because my best friend told me what that was.

She saw the data, the weight and the height of Elodie after she was born. And she goes, Steph, you had [00:07:00] IUGR. And I was like, what? Did they ever say that to you? I said, no. We found out my daughter had growth restriction after she was born.

She was tiny, had stopped growing after a certain point, but we never had growth scans afterwards. So that's how we learned that my daughter didn't grow, And which kind of defeated the whole plan of having her stay in me as long as possible so that she could grow for surgery.

It was around like 20, 29 weeks when we started realizing things were probably not as ROS as we thought they were gonna be.

Joanne Stone: How did, with your medical background, with your expertise and also just being first time new parent, how did you deal? What was your mechanism for dealing with this degree of stress?

Stephanie Lee: Sure. So I was told repeatedly that I didn't have to make any lifestyle adjustments. I am very often on my feet, managed multiple units at the time. Very active person, so I was told I didn't need to really do much. Maybe take a little easy, but not anything starkly different.

No bed [00:08:00] rest. My best friend was the one who was like, Steph, you need to be on your feet with your legs, like you need to be sitting, but she's not my doctor. I think there's also this like pressure when you're a healthcare worker to not be that patient.

To just trust your team because you hope that your patients will trust you, I didn't realize I had this unconscious bias that didn't actually ultimately work in my benefit, that I just trusted folks blindly knowing that, oh, they must have my best interest in mind, which is what we all hope for, right?

Joanne Stone: Can you walk us maybe through I know it's hard and I don't want to bring up, but maybe walk us through that very moment when it was clear to you that that's something was wrong.

This is when, when you found out that Elodie had passed.

Stephanie Lee: So, I was actually just at my normal 36 week appointment. I didn't actually think anything but. I remember that day because I went into work late that day. I had a morning appointment. It was my 36th appointment.

I had [00:09:00] just seen the MFM that prior Thursday, and it was a Wednesday and it was a beautiful day. The sky was like very light blue. It was it was October. It was very crisp. I take the bus up. And I had just gotten off the bus.

My husband met me at the doctor's appointment, 'cause at that point I was like, I used to city bike a lot. I used to do a lot of that when I was pregnant and know I was far along enough and big enough that like I needed to take the bus.

And my husband met me at my bus stop and we, or by the doctor. So I walked in. Everything was fine. Went into the doctor, one of my coworkers mentioned that I had said that I'd never felt her move. She mentioned that to me after the fact.

But again and I remember that moment, I, people would ask me and I was like, I don't really feel her move, but the doctors told me it's okay. And I had shrugged it off and she herself was like, are you sure there's nothing wrong with that?

And I said, it's fine. And I went to my doctor. Sitting in the room [00:10:00] and the doctor, the ultrasound, the bedside ultrasound, and she put the probe on and normally we would hear the heartbeat.

It was like dead silent. And we saw her profile, we saw her body, but it wasn't, she wasn't moving. Just dark and just her profile. And then the doctor got really quiet and she said, I'll be right back. She stepped out. It was just me and my husband.

We didn't think anything of it and we're like, huh. Something just didn't feel right at that point. And I think that's part of the shock is when you really, it just comes outta left field. You just didn't expect it.

She had her coworker come in, another physician, and she put a probe on, and again, just searching and they can't find her heartbeat. And then she told me, I just started screaming.

Joanne Stone: So awful.

Stephanie Lee: And they left us in the room. I couldn't stop crying. I was just like hysterical. [00:11:00] And they just left us there. And then a little bit later they came up and said, told us what to expect next step.

They said, when you're ready, sometime today, you should go to this hospital and check in. Cuz you're gonna have to deliver her. Again, I had no concept of what that meant. Nobody tells you that you have to deliver a dead baby.

And I didn't know if it was like, you have a cesarean, would I have to vaginally deliver? I didn't know. What do you mean I have to deliver a dead baby? I remember we finally walked out.

I was just like, really eerie. I like I still remember the office in the hallway just felt really lonely.

Joanne Stone: Sounds like there wasn't much emotional support at the time.

Stephanie Lee: No, it was very sterile. I still can vouch that there was only one physician who I felt was like, so [00:12:00] supportive and was my admitting physician that was there that day who was covering the floors.

She was an older woman and she was really just she took her hand and she like rubbed my thigh for me when I finally got settled in my bed and reassured me. That was probably the most tender interaction I had throughout my entire stay, at least with the physician.

After that, it wasn't that great. I took my husband and I took that same bus down home knowing Elodie had died. And I think part of us thought that maybe it was wrong. Just, I think there's still part of us that was like, no, there's no way she's gone.

And I think there was a part of me when I checked into the hospital hoping that it was wrong and I asked them, I said, are you sure she's dead? Are you sure she's gone? Can we double check? Can we triple check?

Because I couldn't believe that somebody who was inside me growing was just gone all of a sudden. I'm an ICU nurse, so death is [00:13:00] not something new to me. My grandfather had just passed earlier that year. I had just found out I was pregnant and then he passed away.

I was extraordinarily close to my grandfather and he passed knowing that I was pregnant with her and he had apologized to me that he wouldn't be able to be with her.

Joanne Stone: Oh. Just devastating.

Stephanie Lee: But yeah, I just, I remember like there wasn't much emotional support. It was just very sterile and they put me in this gorgeous room, but it was like off at the side. But other than that, nobody really tells you that these things happen. It's just like process.

So much time has passed. Elodie's birthday's coming up this month. October's Pregnancy Loss Awareness Month, right? And Child Loss Awareness Month. And it's so weird how that kind of all lined up, but resources have changed.

She's gonna be four. [00:14:00] She would've been four this year. Like, four years is a lot of time for things to happen. I have two more kids after her so yeah. I would hope there's more development.

Joanne Stone: Yeah. And certainly I think things have changed to a certain degree, at least for us. But I think obviously we need much more change, and advocacy. But let me ask, you mentioned that, you have two more kids that only need them.

When did you start to think about trying again?

Stephanie Lee: It's interesting. That like mental health kind of component is so big and it can manifest in so many different forms and ways, like the fear's debilitating.

And so any woman or person who I think is willing to try, I think takes an insurmountable amount of courage. And also for like partners as well. I think

that kind of courage you're [00:15:00] taking a leap forward towards something that you're so scared of.

I remember like when I lost Elodie, I cried in her room and there was a point where I felt I went on a nap and my whole family had mobilized together and moved all of her furniture out while I was napping.

'cause they knew I would never have let it go. But they wanted to help me deal. And we both are Asian, my husband and I. And it's a lot of removing the bad stuff.

And I just remember there was this overwhelming sense of I don't want to live, I don't wanna die, but not being with her is just overwhelming and I can't see beyond my pain in front of me.

And again, you don't wanna kill yourself. You don't wanna hurt yourself. You don't wanna die in that sense, but you just don't wanna be alive, because it's just so overwhelming. And so to make that step to try again is just.

It manifests so many different ways. It was an obsession. I [00:16:00] wanted to have a family. I remember distinctly, I had a moment with my husband where I said, I was pregnant with Ellen.

And I was like, I always just wanted one kid. I always just, I was drilled in my head by my parents that children are a big responsibility. You should only just have one. That was like the narrative always.

So I always thought I would have no kids or one kid and we're good. But my husband's from a family of four, I'm an only child, so I told my husband, I said, I don't think I could live life leaving Elodie by herself.

I think I want another kid after her. My husband was like, okay, cool. And so right after I lost her, I think maybe two months, three months in, I was like, I need to give Elodie a sister or a brother.

Preferably a sister. I really wanted a girl. Gender disappointment is a real thing. Like where you're like, I am fixated on this. I really wanted to provide a sibling. It wasn't a replacement, I just wanted someone to complement [00:17:00] her.

And we started looking into different options and that's when ob gyn, there's no like place you can concentrate, a place where you're like, what's the best doctor in this area to go see for this scenario?

It's I realized in doctor referral world, it's a lot of word of mouth, a lot of referrals, like through relationships, like connections and networking. And so I'd heard about Mount Sinai and actually your name a few times.

I knew which kind of personality I didn't want, and so somebody had told me like, Dr. Salsbury conservative in her practice, but that's a good thing. In our case, she saved my daughter when she was 36 weeks. And I was like, oh, okay.

And and then my best friend's the one who told me about her preconception consultation, and so that's how I started my journey, but we were terrified. We didn't know if this would happen again.

Joanne Stone: It's one of the scariest things, it's like that idea that people have, especially when you lose your first pregnancy, right? Am I ever gonna be a [00:18:00] parent? Is this ever gonna work?

Stephanie Lee: You want it like, and I have nothing against adoption. I think it's absolutely beautiful, but it's not the answer. Like people are like well, if you can't, there's so many children out there that could use good parents and you're like, and yet you have all your children.

Okay, thank you. Yes, I do agree. There are many children out there that need good parents. I a hundred percent agree with that, resonate that.

But there's also this sense, like when I held Elodie, like I saw bits of myself, I saw it's a little narcissistic, egocentric in a way, but like you see elements of my husband and my daughter, and elements of yourself, your mom, your dad, and it's just life changing.

Like even for a dead child, I saw that. Like I couldn't imagine what it's like to raise a child, living, breathing, growing, evolving in your hands and your arms. And I think that hope is what kind of drives you.

And like, you learn I learned that just 'cause [00:19:00] you lose one doesn't mean you're guaranteed ever to lose again. And you hear about these stories from other parents. Of all the loss that they've gone through, and some don't actually end up with the child ever.

And so it's just very humbling.

Joanne Stone: Everybody knew you were pregnant, right, at work? And how do you go back there and deal with all the questions and

Stephanie Lee: Sure. So right after I lost Elodie so this is where you're like control can you control, what can't you control? I made a very conscious decision shortly after LDI was born to make an Instagram post on my account, telling the world that she had died.

I did not want to deal with the awkward questions of How's the baby? Oh my gosh. I still dealt with it. But I figured if I could control as much as I can, this is one area I'm going to control what they hear, what happened.

So very quickly [00:20:00] I posted it. The amount of love and support that just flooded in was just like, just so humbling. And that's just 'cause I'm a very open person. My husband and I are very open individuals. I know a lot of families who are very private and that's okay.

So for me, I got a lot of support that way, but it had to do with the deep need to have, to control what information was being fed out to the world.

I very high risk for postpartum depression. I, geez, I don't know what could happen. The amazing support of my manager, my director, I went back to work in two and a half weeks postpartum.

And I also knew I wanted to have another child, and so I didn't wanna burn all my time potentially because of my situation when I may need it down the road. I didn't know antepartum if I would have to be in bed rest. I didn't know any of this stuff.

And this, again, this is like the nurse brain in me, [00:21:00] the manager brain in me, where I was like, oh gosh, I don't know what's to come. And so I ended up coming back at two and a half weeks.

Joanne Stone: It's really one of the tragedies I think in this situation where policy makers are making decisions about not supporting patients who have had a stillbirth or loss, and no parental leave, and you can't take FMLA because there's no family member that you're taking care of.

Stephanie Lee: A hundred percent. It has to be for yourself, quote unquote. But then you need to have a diagnosis to justify why you need that leave. And depending on some places where I, again, every organization has things a little bit different, but certainly not made for loss.

People still call my stillbirth a miscarriage. And not to minimize that by any means. I am truly a believer of a loss being a loss. But it does look different. The healing process works a little bit different.

Yeah, there's a reason why after [00:22:00] 20 weeks it's called a stillbirth versus a miscarriage. It's just different. And the time and the healing looks different. That's not even to include the mental health component that any woman who's going through fertility, I've seen my friends through IVF. It's a lot.

Dr. Stone, I just have a quick question. Is there a difference between how women are, patients are cared for miscarriage versus still birth. I've seen so much stuff anecdotally personally, but again, I don't know what that's like on a care management standpoint.

Joanne Stone: No, it's a great question. I think a lot depends on the cause of miscarriage. So if we're talking about maybe a six week miscarriage, they sometimes still need a much greater degree of support 'cause they're still affected by that.

But, you are not going to be doing the same degree of care like that we talked about with all the testing. We coming in every week, starting 28 weeks and all those extra visits might be different. Miscarriage [00:23:00] for anybody who was hoping to have a baby is difficult.

Some people handle it a little bit more easily. Just knowing how common miscarriage occurs in 20% of all recognize pregnancies. So it's not uncommon, but for some people it's just devastating.

I remember I had a patient that came for a Rainbow Clinic preconceptual consultation, and she had one early miscarriage. And to her, that was just her child that she lost and she was really sought out, the care on the Rainbow Clinic because for her it was, but I think again, a lot depends on the cause.

Also, gestational age. When you get to 36 weeks and you're thinking, you're so close. There's so much anxiety that occurs around that time. So they are, they're different. Yeah. But share overlap for sure. I,

Stephanie Lee: I've, I, that I know of, I've never had a miscarriage, but that fear was so high in my subsequent [00:24:00] pregnancies with Elodie, but I think with Ethan, actually my pregnancy after my third pregnancy, it was like paralyzing fear.

It was like early on, and I think I ended up calling the line that was provided a few times because of it. I was so scared. I, and I don't realize it until after it happened, because I never experienced a miscarriage myself.

And and that's why I say it's not the same, but in the sense that fear and anxiety and hope is still wrapped up so tightly in there. And I was so scared I would have a miscarriage with Ethan and I thought I was, I never thought I was gonna be like, safe from the fear, anxiety, but man, I, you learn it, it just manifests differently.

It looks different, but it, the elements are still there. And, oh man, like with Elia, the healing process, the pregnancy looked different. With Ethan, [00:25:00] I was almost in the clear and not in the clear, and so I didn't realize how much my fear of miscarriage was going to be with such a subsequent pregnancy.

Joanne Stone: That's really, yeah, it's very interesting. It was just this morning I have a patient who, she's first trimester, she's, in the Rainbow Clinic. She already delivered a healthy baby, at her Rainbow baby after. But she just called this morning, saying she needs to come in for scan.

She just wants to make sure everything's okay 'cause maybe it's that sort of that feeling like, okay, is lightning gonna hit me again, and i n a different way?

Stephanie Lee: Yeah, exactly. Exactly what it was. Unexpected way. Yeah. Yes. That's exactly what it was. Yeah, no and that's why it's losses. I believe loss is loss. It just manifests differently. But yeah it is different. Yeah.

Joanne Stone: Yeah. Alright. Just talking a little bit about, the Rainbow Clinic itself. How, did you find what was, or what was the most meaningful X factor for you in being part of it, do you think?

Stephanie Lee: To be [00:26:00] honest, out of everything, it was the physicians and the sonographers.

The MAs are great, by the way. I love your MAs, but what was so markedly different from my first experience and just watching things, hearing people and everything was, I still remember with DY when I would have an MFM appointment, I never saw a doctor.

I had to beg. I had to wait hours to see somebody. It was always the nurses. Nothing ever went smoothly because my SSTs were always prolonged, my bpps were always inconclusive.

But at the Rainbow Clinic for me, that even if it was short, even if it was like a minute or two, that facetime I had with a physician and then like with, Ethan, I had a PA as well, but just having facetime made such [00:27:00] an impact.

The sonographers also I remember with Elodie, it was like pulling teeth trying to get a sonography appointment. They had a lot of issues and one sonographer I remember took the prone, bounced it on my belly and goes, Dance, baby, dance.

And it was like really weird. I was like, funny but weird. And I was like, oh gosh, this is a little aggressive. But in general it was just like very sterile and nobody explained anything. It was just like rushing to get the numbers in and measurements and that was it.

But I like to build a relationship with our sonographers. I loved meeting them. I loved talking to them. They explained everything so well. And like they never felt annoyed. My husband's big thing that he fixated on after Elodie's loss was AFI measurements.

That was his thing. "Does the placenta [00:28:00] look good? And what's the a FI look like? What is it? Where are we at? What's the percentage?" Or we, he was so fixated on that and I understand why.

He's a data guy. It's a number. Never once did we ever get any kind of annoyance, just like the intonation, the support, oh yeah. It was just very matter of fact. And that was like so reassuring for us as a family.

And like those, that those two factors were just pivotal and I, that's why I cannot rave enough about the clinic because that patient education element, you it just as you're scanning and talking out loud. It just makes the world's difference.

Joanne Stone: No, I think the physicians and the sonographers are just they are amazing. And truly, it's real how they feel about making sure that you are okay. And to communicate to you like, this is not hap, it's not happening.

You're not getting amnios, [00:29:00] baby's moving.

Stephanie Lee: But even if there is something wrong, cause I developed other complications, but like you felt supported. I think that's something that's different. Accessibility, presence. Doesn't have to be very long. I didn't need 30 minutes an hour with somebody.

Even a couple minutes made such a vast difference. So when people ask me and for recommendations, I say Doctor Stone's my doctor, but I can wholeheartedly tell you, I can vouch for every other doctor in the clinic.

I was like, this doctor was in the room and I delivered this kid. And then with my other kid, this doctor and this doctor was there for my other kid. They were all wonderful and Dr. Stone is really busy, so sometimes I had my appointments with this doctor.

And it was, I've never been disappointed and I really mean it because the whole team is so cohesive and so supportive and just the bedside manner is just out of this world.

And I've referred many friends and many folks, even those I don't know, to the clinic, because I don't think there's a single doctor there I [00:30:00] don't think I could vouch for. Everybody was so wonderful.

Joanne Stone: Thank you for saying that. And now, you are giving back in being a mentor. Tell me a little bit about that.

Stephanie Lee: Sure. So our social worker through the clinic, I was really lucky 'cause when I was pregnant Elia, she had just started the role and I think she's put so much work for towards like building this program and, just, one of the biggest strengths that I got postpartum, even before I was pregnant with Elia was, there was a mom I was connected with from California.

I've never met her. I've spoken to her on the phone for hours, but she's about 10 years ahead of me. She was Korean American like myself. She's also a nurse. She lost her first child as well. And she had three children afterwards.

So she's had a total of four children and she gave me hope in being able to have a family and how to [00:31:00] incorporate my first loss into our family. So for her, her son really defined how she built her family around.

She has three living children afterwards, but just watching that was just so inspiring for me, and I found that moms who have lost any shape or form or struggle, there's just this empathy that you can extend to one another in this community that you can't, it's not tangible, you know what to say.

Versus like somebody whose intention is 200000% there, but sometimes the delivery just falls short and it's not their fault. And I think with the mentorship

program, you're giving people accessibility to people who had that shared experience, which I think is like so powerful.

For me it was like randomly connecting with a woman [00:32:00] in California. But not everybody has that.

Joanne Stone: Yeah, no, it's been an amazing program, to be able to serve as a mentor to somebody that's going through, what you went through and just wonderful way that you're giving back and continue to, it's part of who you are.

You're such an empathetic, caring, but strong person, and just wanting to, just like you take care of patients or, in the ICU you used to, now you're more administrative, but that's part, that's who you are.

Stephanie Lee: I've been very fortunate that I have an amazing community. I've been so fortunate to meet you and the team and, the stillbirth community is very vocal, but also very supportive of one another. I met a lot of folks through Instagram.

I did the documentary and just the push team, Push for Pregnancy, those women also, just, there's been so many people in the community that are so supportive [00:33:00] of one another. And I think it's just like we all know what that's like to go through and we don't want that for anybody.

I actually never liked advocacy. Can I? That's like my guilty, a confession. I actually never really did any political anything. I never really liked to say what I believed in. Rarely ever did any kind of advocacy.

I just figured I'd just do my community service, give back that way. I was never really one to advocate for things. I have faith, but evangelism is definitely an area I'm like never comfortable with.

Like afterwards you just have this kind of like p superpower that you just didn't even know you had. Somehow I am now here, but it was definitely not something I ever was interested in or ever did until after we lost Elodie.

Joanne Stone: And I think that's true of a lot of people.

It's like a life altering event that changes your thoughts of what you wanna do and how you wanna try things. But

Stephanie Lee: [00:34:00] But it's wild. There's a woman out in Patchogue, Long Island, and she does this like baby vigil. She does a lot of a advocacy and work for like supporting lost families in different, pregnancy mis like stillbirth, miscarriage your child, like in that whole field.

But she herself never lost. And then, like folks who work for the Rainbow Clinic, you like it, it's, I think it resonates beyond just, you don't have to be someone who lost. It's just like something just touches people and then just like the village that's behind there, I think is like so powerful.

Joanne Stone: Yeah. Yeah. It's just one of, I think the one of the most devastating things that can happen to somebody that just comes out of off and out of the blue and so unexpected. It's really difficult. So I think. Most people who have a bit of a heart would want, would wanna support this kind of, I don't,

Stephanie Lee: do you watch call the No [00:35:00] Midwife by any chance?

No. The PBS special. I think they're like on season 12 now. Call the midwife. Call the midwife. It's about it was like in the 19, I think forties, fifties maybe. I just expanded a lot. We're 12 seasons in. Yeah. But it's based in like the slums of London. And just serves a very poor population and they rely heavily on midwifery too for birthing.

And there's like stillbirth and then a lot of historical films are like shows you'll watch. Like sometimes stillbirth comes in, they don't call it stillbirth, they talk about losing children or how they had, were pregnant to the end, but they don't have a living child.

And infant mortality was so much higher, not even a hundred years ago. And it's just so hushed. And so I think that. I think more than anything, like I said, I am very fortunate because I speak so openly about this stuff, so when you speak about things that [00:36:00] support comes in because you're talking about it.

But for those who are comfortable with that, like that support can be so hard to get. 'cause not everybody knows that you need that support. So I'm hoping that through more advocacy. People know that there is support. You don't have to be public about it, you don't have to talk about it all the time.

But that there is safe space to be able to be like that. People do wanna know your child's name if you wanna give your child a name and people do wanna talk about quote unquote, unpleasant things because it's not unpleasant. It's actually quite beautiful.

Joanne Stone: Yeah. So Stephanie, I just wanna make sure I give you the opportunity to ask me any questions that you might

Stephanie Lee: Sure. Actually, I do have one question, Dr. Stone. How did you how did you come to wanting to do research and find your. Dedicate so much resource and like passion and work towards stillbirth. Like what brought you here?

Joanne Stone: Yeah. Thanks for that question. I think as a maternal film medicine specialist, I [00:37:00] always. Took care of patients who had, their high risk pregnancies, but part of it was taking care of patients that had losses.

And some of the patients I took care of were part of one in particular, or two of them were part of at that time, pushed the organization for that advocates for patients Yeah.

With stillbirth. And they had it come and approach me and asked me if I would be interested in starting the Rainbow Clinic. Oh. Rainbow Clinics are, they're about over 20 of them in the UK really run by Alex Heel there. And they wanted to start one in United States and start one in New York.

And so they came to me and we spent about a year planning it. And then we opened in March of 2020, I guess March, 2021. I saw you in October, 2020, 2022, I think. And. Now it's really growing and we started a US pregnancy after loss network. And so we have three of us as medical directors and we.

Review applications [00:38:00] to open up a rainbow clinic because we really wanna be, we want it to be modeled in the right way and not just say, have somebody say, oh this is a rainbow clinic. But they're not taking insurance for everybody or Sure. Making sure they're going through training. 'cause there's a lot of training of staff.

Like we train the front desk, we train sonographers that all the physicians in terms of, what's meaningful? Like you brought up, asking did you give your baby a name and do you want us to refer to it? And we put the, the birthday in the chart and things like that. So I actually have somebody is coming tomorrow to shadow me in in the clinic.

And she's from California. UCSF is gonna be the next place to open. Amazing. Yeah. One opened at Columbia at in Utah. And then we're, I think we're gonna be in Pittsburgh, U UCSF. UCLA, probably Hawaii. Oh my gosh. We're trying

to get it to be everywhere. I think Yale may, I don't remember, but eventually we're gonna get there.

That's amazing. So it's it's really exciting and [00:39:00] honestly, one of the most rewarding things to me, is to. Have the privilege of taking care of a patient like you and being part of, your family's life. It just gives me, you'll forever be like

Stephanie Lee: one of the most important people in our lives.

Joanne Stone: You're so important to me. And I, I stay in touch with so many of the patients after, but email or, and so it's a, it's an honor and a privilege. To have your trust. That's what I mean. You were

Stephanie Lee: seeing my

Joanne Stone: faith in

Stephanie Lee: in a lot of my hope in US healthcare.

I'm not gonna lie, it's a pretty bold statement, but I mean it, it. Your efforts are definitely not unnoticed. Like I, I truly believe you're probably one of the pioneers in women's healthcare in this day and age. I really mean that. I think there's so much more work to be done, and it's hard to find somebody good in your corner.

And so I really believe that you're like a pioneer.

Joanne Stone: Part of it is my dad was a psychoanalyst, and I think I'm like, have a little bit of the [00:40:00] psychologist and me, from him and, I growing up would watch him the way he helped so many people and children to adults and just, it was real role model for me.

Yeah. I'm sure he's super proud of you. Yeah.

Stephen Calabria: So a final sign off from you thanking our guest and if people want more information on the Rainbow Clinic fill in the blank.

Joanne Stone: Go a website, I think.

Stephen Calabria: Do you know the the website or

Joanne Stone: you can find it on Sinai's.

Stephen Calabria: You can find it or click the link in the description below.

'cause I'll in the, okay. In the podcast description below.

Joanne Stone: Okay. Stephanie, I cannot thank you enough. You have been so open and honest, and that's who you are, and just sharing your story both today, you shared it on the ProPublica documentary. That people can watch on popup.org for free.

But you're an incredible inspiration. Your strength, your courage, your resilience is just [00:41:00] amazing. So thank you for all you do and for giving back and for being part of today. For those of you out there listening to this podcast, you can find information on the Rainbow Clinic below.

Stephen Calabria: You can find information about the Rainbow Clinic on the Mount Sinai website, or click the link in the description.

Joanne Stone: Okay. For those of you who want more information on the Rainbow Clinic, you can find information on our website or click on the link below.

Stephen Calabria: Click the link click. No, it's okay.

It's alright. Click the links in the podcast description below.

Joanne Stone: Click the link. Can I just say that line? Sure. Yeah. Click the link in the podcast description below.

Stephen Calabria: One more time.

Joanne Stone: Click the link in the podcast description below. Lemme say it one more time. Click the link in the podcast description below.

Stephanie Lee: Oh, crap. That is a tongue twister if there is one. Oh my God. I was like [00:42:00] running it in my house. A click literal.

Joanne Stone: I actually, I think I did write it down, but I just didn't get to it. Okay.

Stephen Calabria: Set it up. Go.

Joanne Stone: Okay. Stephanie, one, one other question for you. What do Ethan and Elliot know about dy how do you incorporate Dy into your family? So she is

Stephanie Lee: a, she's their sister. So every night we pray and. My husband or I always lead it, typically my husband.

And we always include her. We say please God, please make sure that eddy's okay. The kids love playing with my necklace and I have a necklace with Eddy's footprint on it. And they Elle's Korean name is Du and so Elia actually calls it ha's foot [00:43:00] and every year for her birthday. We have a birthday party, so Dy Eddy's birthday's gonna be four this year, but Ella has experienced Eddy's birthday parties.

And Ella actually will point up at her sister's urn and her little mantle and call it, know that's her sister. And Ethan is not quite there yet. But yeah, we, she's just another member of the family. I don't think they fully conceptualized why she's not here or what it means to have a sister or brother like that.

But we're hoping we normalize it. We've, we, I've read that like loss and family members who aren't present, children are very open and they normalize things. So our hope is not to make it a stigma or somebody who we don't talk about, or to just incorporate it as another member of the family.

Joanne Stone: I think that's amazing and I think that's gonna be so helpful for families who have experienced this to know how to deal with it if it's right for them.

Stephanie Lee: Yeah. My hope, [00:44:00] one thing I learned from losing Aldi was that the concept of like hope and afterlife was something I couldn't really conceptualize prior to losing her. And it made things a little bit more tangible for me and

I hope my children Elia and Ethan are more empathetic people for it, and they understand that grief is part of life and that if they can embrace that in a way, I would hope that they could be better people or citizens of the world for it and that they could extend that love and support to somebody who needs it one day.

Stephen Calabria: Thanks again to Stephanie Lee and Dr. Joanne Stone for their time. That's all for this episode of Road to Resilience. If you enjoyed it,

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Want to get in touch with the show or suggest an idea for a future episode? Email us at podcast@mountsinai.org.

Road to Resilience is a production of the Mount Sinai [00:45:00] Health System. It's produced by me, Stephen Calabria, and our executive producer Lucia Lee. From all of us here at Mount Sinai, thanks for listening and we'll catch you next time.