Stephen Calabria: [00:00:00] 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.

On this episode, we welcome Susan Baum, a New York City based voice teacher, diagnosed with age-related macular degeneration, a progressive and potentially debilitating vision disorder.

Susan's long family history with the diagnosis, set the stage for her own. Then a clinical trial gave her new hope-- and a fresh eye on the future. We're honored to welcome Susan Baum to the show.

Susan Baum, welcome to Road to Resilience.

Susan Baum: Oh, thank you.

Stephen Calabria: Now Susan, your father and sister both lived with AMD. To kick us off, what is AMD?

Susan Baum: Age related macular degeneration. It destroys the central vision in your eye by cell [00:01:00] death, essentially in the macula and other parts of the eye to, from what I understand, but it is the leading cause of blindness in adults over 65 or even maybe 55, but certainly 65.

Stephen Calabria: Does the process hurt?

Susan Baum: No, not at all. It's not painful. It's just slow vision loss. And neither does glaucoma or any number of eye diseases, have no pain or anything like that. So it sneaks up on you.

Stephen Calabria: So your father and sister both lived with it? How did they

Susan Baum: Well, my father is passed. He started showing signs of it when he was in his fifties and maybe even earlier. My brother and I were talking about it, and he'd been a pilot. And he was flying and he suddenly got double vision and they grounded him.

And we think that may have been the beginning of his eye problems, but my [00:02:00] brother noticed it, particularly in his fifties. He was playing tennis with him one night and he couldn't hit a ball to save his life.

And that was the big reveal, and my sister, she's still living. She started noticing the computer was acting funny. She was working and she was diagnosed and they ended up having to get her large screen computer monitors and things like that while she was still working. That was 13, 14 years ago now.

Stephen Calabria: And so they were diagnosed with this condition that they knew to be genetic. How did their experiences shape your understanding of what might be ahead for you?

Susan Baum: It meant that every time I went for an eye exam, I was scared, because is today the day I'm gonna get a diagnosis? And then finally one day I did. I was hoping that I'd somehow dodged that particular bullet, [00:03:00] but no.

Stephen Calabria: So could you tell us a little bit about what you do for a living?

Susan Baum: I've had my own vocal studio for 26 years. I operate out of the film center building on ninth Avenue and 44th Street. I've been there since the beginning. I made the decision when I started my studio to specialize in beginning singers, because New York is full of professionals, but it's hard to find a teacher if you really are scared and don't know if you can do it, even.

So I made the decision to teach beginning singers, people who don't even think they can sing. And it has been my great delight. There is almost nothing like somebody's face when they open their mouth after doing the exercises for a period of time, and out comes a sound that they like.

It's wow, I did that. I say, yeah, you did. And it's really wonderful. And. I've never regretted that decision. And, [00:04:00] it's joyful, it's confidence building for people. They figure if they can do that, that they've been terrified their whole lives. They can do a lot of things.

And so it's very confidence building and as a result, very happy making for me. My, like all my studio, my happy place.

Stephen Calabria: And I imagine too, for people who've lived their whole lives believing that they could not sing, where this was just not an ability they could ever have, it must be incredibly satisfying for those people.

Susan Baum: The way I describe it I do a class called The Basics of Singing for Non Singers, and one of the myths that I put up on the big screen TV is myth. People either believe you're born with a good voice or you are not. Nothing could be further from the truth.

And because the larynx behaves like muscle tissue, if you exercise it routinely in particular ways, it can be strengthened.[00:05:00]

And to the point where, a guitar string if it's slack goes but if you tune it up nice, goes ping. Same thing is true of the vocal chords. If you train them and they become more muscular, more toned, they make a nicer sound.

Stephen Calabria: Many laypeople might think to themselves Ray Charles and Stevie Wonder did it without vision at all. Why is vision required for voice teaching? One would think if anything that the opposite would be true.

Susan Baum: Again, those are very specific performers. And for example, Stevie Wonder came to be a star when he was a little kid and his genius was just immediate and there. And again, I wouldn't mess with something like that.

And there are people who are that special in their own way. And Ray Charles the same thing. I wouldn't mess with that voice either.

Stephen Calabria: But the point is they did it without vision.

Susan Baum: They're doing everything with their [00:06:00] ears. There are three ways that people learn. One is with their eyes, one is with their ears, and one is kinesthetically. And I would argue that those two gentlemen learned everything with their ears and they're so wonderful as recording artists.

Most people listen to them. They watch them rarely in concerts and on film and stuff like that, but most of the time you listen to them. So it doesn't matter if they have peculiar body movements or something like that.

But if you're training Broadway people or people who wanna sing in a chorus, that kind of behavior's not helpful. So, if I've got singers in choirs, for example. You don't want people in a chorus doing strange movements.

I don't want people getting up and auditioning for a specific job where those kinds of ticks, movements, whatever you wanna call them are gonna keep them outta the running for the job.[00:07:00]

See, the two gentlemen we were just discussing have their own style of performing and that's what they've been doing since the beginning. They're not trying to fit into a particular genre of music.

They are individuals in their own right and they were able to cultivate the support system to showcase them to their best advantage, always.

Stephen Calabria: Before your diagnosis, did it ever feel like you were living with a clock ticking in the back of your mind?

Susan Baum: Absolutely. Yeah, absolutely. But I had, because of my dad and my sister, and because I loved them so much and cared about them, I had started doing research online through NIH clinical trial registries and things like that just to see, because there was no treatment except the AREDS vitamins, which NIH had come up with years ago.

And that was just supposed to slow it down a little bit, but there was no real treatment. [00:08:00] But I kept looking at the websites about what clinical trials were coming down the pike and there were all kinds of things going on in the research world about it.

And if you study clinical trials, you learn that some of them come and go because they put it up a theory and they start to do the testing and then they say, this isn't working, and they take it down or this is interesting, let's keep going.

And the major ones, there was one there was stem cell research that was developed in Japan but that is a long ways down the way, and the treatment that they have now is like a million dollars a person.

It's like ridiculously expensive and they were then there were these shots which eventually became Izervay and Syfovre, which are effective at slowing down the progression of the disease.

But I kept looking at articles and research about red light therapy. And I had been doing research on the [00:09:00] red light therapy for a long time, hoping that it would reach a state of development where it could be helpful to my dad and my sister.

Unfortunately, my dad passed away before it came available, but my sister's still here, thank you.

And I've already told her about the treatment and I'm fingers crossed that maybe she will be able to participate in it, but it looked the most promising to me from my perspective. So when I got my diagnosis, I was even more interested in the research.

Stephen Calabria: So you received that diagnosis in 2023. What exactly was the diagnosis and how did it feel?

Susan Baum: I had the beginning stages of AMD but in my left eye, my right eye is pretty good, if not really good. But I got the AMD diagnosis, and then a year ago I got the geographic atrophy diagnosis, which is the worse, more advanced stage of the disease.[00:10:00]

And about that time was when the eve and ovary shots came on the market. And I talked with my doctor about it and he said you're not at a stage where you need that.

You, we'll keep an eye on it for you, but we didn't start the shots at that point. I know they're out there and people are getting them, but we didn't start them on that.

Stephen Calabria: As a voice teacher, how did your vision challenges affect your work?

Susan Baum: There were two major ways. One is, no matter what I did with my glasses, whether it was reading or mid-range or whatever, I was having difficulty reading chord symbols on sheet music, and the lines of the staff were slightly wavy, which makes it difficult to read the notes. So that was a big one. And I was having to write the letters in bigger letters with Sharpies so I could see them [00:11:00] better.

The other thing is that a MD takes away your central vision so that when you look at somebody's face, it gets mushy. And if I can't tell what my clients are doing with their faces while they're singing. They could be doing something really wackadoodle and I wouldn't be able to tell them.

I wouldn't be able to say, do you know that you're doing this with your jaw? Or, do you know that your forehead is all the way up into your hairline? That sort of thing. And it was getting harder for me to tell that.

Stephen Calabria: You've described feeling like your diagnosis was a doomsday scenario. Can you share what that feeling of despair looked and felt like for you?

Susan Baum: I watched my dad's world shrink as he became more and more blind. He became. Less and less confident about moving around even his own [00:12:00] house. He had a chair in the dining room set with casters on it, and he just scooted himself around because he was afraid of tripping over things.

And his world just became very small and I'm not interested in that for myself. And my sister fortunately has four children and five grandchildren, all of whom live near her. So she has a lot of company and a lot of people to spend time with, and she doesn't mind being in her house a lot.

That's not for me. It's just not for me. And I remember my doctor telling me you'll be able to get around. And I'm going, I really want more out of life than that. My brother and I travel and we have such a good time seeing other places and other [00:13:00] people and all different kinds of scenery and stuff like that.

And to think that was going to be taken away from me, since it's such a source of joy, our travels together it was okay, what kind of accommodations am I going to have to make? And I was not looking forward to that.

Stephen Calabria: So you were doing research all along for your father and your sister, and then you received your own diagnosis. And what did you uncover?

Susan Baum: The clinical trial that I was following was called Light Site three, and it was the red light therapy treatments, and they were, it was three times a week for three weeks, and then a break, and then another sequence like that.

And while the shots for a MD were [00:14:00] slowing down the degeneration, they weren't doing anything to improve the vision, the visual acuity, but the red light therapy clinical trial. Clearly said that visual acuity was getting better in the people who were getting the treatment.

That excited me. And so I was following the light site the clinical trial. And interestingly enough, election day of 2024, I was up all night and I suddenly realized, I don't even know what the delivery system for that treatment is, maybe I should look that up.

Cause I didn't know whether it was a machine as big as a house like the old computers used to be, or so I didn't know what it was and I went online and there was the press release for the Lumi [00:15:00] Thera red light therapy machine, which had just gotten FDA approval that day, and there was a picture of the machine itself, and it looked a little bit like those old time opaque projectors.

It was a thing that would sit on a table or a desk. It was just, and I'm going, that looks manageable. And not only that, but it was just approved by the FDA, so they think something's going and I was like so excited. I was so excited. I was up the rest of the night.

I was writing a letter to my retina doctor and going like this, and Did you know about this? Did you know about this? And I copied the clinical trial report and the whole thing. And the very next morning I ran it over to his office at the New York Eye and Ear infirmary and gave it to his people.

And I said, you have to show him. You have to show him. Because I was so excited. It was so hopeful to me and he must have thought [00:16:00] I was outta my mind, but he knew Dr. Rosen. All the guys at the New York Eye and Ear know each other.

And so, he said we knew that Dr. Rosen was working with this red light therapy. We weren't sure at what stage of development it was. And there it was approved by the FDA and he said, I think it's time for you to make an appointment with Dr. Rosen.

And so I did, and that was back in January and he did all his intake on me and I said, yeah, you're a good candidate. And I said, okay. He said I don't have the machine yet. I should have it in about a month.

Stephen Calabria: You were skeptical at first, I imagine, somewhat, given that there were no real treatments for early AMD, or were you?

Susan Baum: No, I, based on the light site three clinical trial and the thing that was maybe most exciting to me was, you know about the way clinical trials are set up, there's different cohorts and this one gets so much of the treatment, this one gets so [00:17:00] much of the treatment, and then this one gets what used to be called a placebo now called a sham treatment or whatever.

And so there were three different buckets, if you will. The sham people, because it wasn't a pill or a shot or something. This was light therapy. So they had to be getting something or they would know they were getting nothing. So even that third group that was getting sham treatment showed improvement.

So I went, that's the published findings. Since then, there has been a second trial called Light Site three B, which used a hundred people from that original study, and the improvements have continued for those people.

Stephen Calabria: What was the experience like sitting down for you for the first [00:18:00] session?

Susan Baum: It was really charming, actually. The machine is cute, it looks like a large coffee maker now, and so it's not scary. It's just, very tidy little machine, and Dr. Rosen came in and he went on the other side and adjusted the things. And there's lights.

They do one eye and then they do the other, but it's not painful. It's not noisy. I didn't know to expect any noise or anything. There's a couple of clicks that happen during the course of the treatment, but it's essentially very. Calming if I can say that. So it was not alarming in any way.

Stephen Calabria: We like to talk about on the show often is the idea of facing fear, what a big role that plays in people's resilience. Was there any element of fear for you as far as going down this road to try to address this this problem?

Susan Baum: I would say my [00:19:00] biggest fear, and I've, I talked to my brother at great length about this. I'm a very private person. People in show business tend to be very private people, particularly about medical conditions.

And initially I only told family and close friends that I got this diagnosis. There are many of my clients who do not know about it. I have not told them. And when Alexandra asked me to do the article for the Mount Sinai annual report

Stephen Calabria: Our colleague Alex Bissett, who's amazing.

Susan Baum: Absolutely. And lovely, just lovely person. When they asked me to do that, I said, I know this is mostly targeted for medical professionals, but like with the social media, once you put something out there, you can't take it back.

Nobody knows where it goes or why, [00:20:00] and I thought about it for a couple of days before I answered her back and told her I would do it. I said, forgive me if I get a little emotional here, the benefits of this treatment for many people.

It is much bigger and much more important than any fears I may have about my own privacy, and I decided to go ahead based on that. And I have told several friends in the meantime.

And their immediate reaction was, is, oh my God, my dad had it and I'm afraid I'm going to get it. Can you give me all the information? And I went, of course, I can give you all the information. Happy to do because of 70% of all a MD cases are hereditary.

And the other thing is that, as part of the [00:21:00] ongoing research for this, which I will be for the rest of my time, is that my sister has four children and five grandchildren. I don't have children, but she does, and I don't want them to go through this hereditary disaster.

And if there's things I can do to prevent that, I think that's more important than my fear of being thought of as damaged or invalid in any way. 'Cause people treat you different when they think you have something.

Now, what I have is not life threatening, but it can be because people in the advanced stages fall down, break their hips. They, that's the beginning of the end for them it can be a, without being a causal factor, [00:22:00] a contributing factor to decline, to serious decline.

And there's a lot of people out there with this. I think last count was 18 million in this country. My biggest fear was, oh yeah, I guess I have to go public.

Stephen Calabria: Before we continue, I just want to applaud your courage in doing that. It's not easy to come forward about anything that's going wrong in our lives, especially when we're one of the first people to ever come forward about it.

It took a great deal on your part to step forward and be one of the first to receive this treatment. So we're very appreciative of you. That all being said, the therapy worked or at least it appears to be working?

Susan Baum: Yes.

Stephen Calabria: What was the moment you realized it was working?

Susan Baum: It was after the second treatment [00:23:00] of the nine, the first nine. A neighbor of mine and I get together for dinner once a week and we had been watching delightful television show called Tokyo Stories, so it's in Japanese.

So we had to read the subtitles, and the subtitles were getting harder for me to read and I had the treatment on Monday, treatment on Wednesday, dinner with Diane on Thursday, and we sat down to watch a show and I went, oh my God, the subtitles are clearer.

It was that fast and I'm sitting there. It was the same tv. I was sitting on the same seat, same distance, and the subtitles were clearer.

Stephen Calabria: Making out buildings of skyline is one thing. Reading subtitles, that is major.

Susan Baum: Yeah, it really was. It really was. [00:24:00] And so that was a big deal and it was pretty immediate.

Stephen Calabria: And in addition to that, you've mentioned being able to read sheet music again and seeing the kind of lip of the subway stairs more clearly. So how did these everyday improvements change your sense of safety and confidence?

Susan Baum: It seemed to affect my depth perception because the edges of the stairways were slightly distorted. It was hard for me to tell exactly where the edge was. Now, I don't have that problem. The edge is very clearly defined now.

And so even though I hold on to the railing at all times because people rush past you and I just wanna be sure I can catch myself if I get bumped into, but it's not because I can't see which step is next.

The stairs are very clear to me now, and that means I can move [00:25:00] much more confidently up and down stairs without being hesitant and feeling my way, which is, it's a big benefit.

Stephen Calabria: Of course It's.

Susan Baum: You don't have to feel your way and you don't have to be a little in what? In trepidatious. Yeah, trepidatious. That's the word I'm looking for. But it, and that was the, I think the second week. The second week.

Stephen Calabria: And beyond the physical improvement, what did it do for your emotional health and resilience?

Susan Baum: There were two times that I thought I was gonna lose my studio. One was with COVID, and you talk about resilience. A lot of my clients lost their jobs. We couldn't be in the same room.

I discovered Zoom, and as a result of learning how to do my classes on Zoom, I was able to keep my business going through the COVID lockdown, [00:26:00] and now I have clients all over the country as a result.

So it actually expanded my business and the second time was when I got my diagnosis, thinking that I was going to have to give up my studio at some point that I was gonna have to close it down. I don't believe that anymore.

Stephen Calabria: How do you balance hope with realistic expectations as you continue with the therapy?

Susan Baum: I think because it's early days in the development of the technology, expectations, we don't know what we can expect yet. Realistically, I've already experienced improvement.

So, I told Dr. Rosen, I said, even if I only get to keep what I have today, if we can make it possible for me to keep the vision that I have at this moment, I'll be good with that. [00:27:00] I'll keep taking the treatments and doing whatever, because we don't know.

It's still too early to tell with this technology how far it can go. So I'm hopeful that I can experience whatever is possible in this technology. I, my diagnosis was relatively new in my life when I hooked up with the machinery and Dr. Rosen.

So, one thing they have mentioned in the reportage is that it would appear that the soonest you can get this therapy, the better the chances of results would be. But who knows? It's very early days.

But I told Dr. Rosen, I said, if we can just hang on to what I've got, I'm good with that. I'm really good with that. And I told him, I said, you'll never be rid of me. [00:28:00] I'm yours because I wanna be part of that research.

I wanna, I can't be a big philanthropist with a major donation of money or anything like that, but by golly, I can be a Guinea pig. and I'm perfectly happy to be a Guinea pig in this.

Stephen Calabria: Would you say that the treatment changed the way you think about science and innovation in fighting hereditary diseases?

Susan Baum: I wouldn't say it changed it because I'm a big believer in science. I trust science a lot and the people who do it. My brother's an engineer and he spent his whole life trusting science, and I learned that from him.

Even though I'm an arty type, I've been in musical theater and film and television and now singing for the last 26 years. I'm artistic, but I, but interestingly enough, music is mathematical.

So it, it [00:29:00] counts. It counts. So I believe in numbers. I believe in science. I believe in experimentation. I believe in failing. I, you don't make an omelet without breaking a few eggs, sort of thing. You gotta try things.

And that's why I was following the clinical trials. And like I said, a lot of them fell off the radar. They'd get a theory and they'd try and it didn't work, and that away it went, it wasn't feasible.

Stephen Calabria: Not every clinical trial will necessarily succeed. They're trials for a reason.

Susan Baum: For a reason, and that's why I kept following the research and when a new one would pop up, I'd see how long it would take and I'd go back and look you to see if they, 'cause I could tell, I kept copious notes about them, how long they were scheduled for.

I also looked at, would I be a candidate for any of the ones that were coming up? 'cause you can look and see where they're enrolling people for clinical trials too. And because I didn't have a diagnosis, I wasn't a candidate for [00:30:00] most of them.

And by the time I was diagnosed, a lot of good things had come together, which is exciting. It's a whole new frontier in hereditary disease. We've got gene therapy now. I don't know where that's liable to go.

Stephen Calabria: Looking back at the depression that you felt following your diagnosis, what would you tell that version of yourself now?

Susan Baum: You faced other challenges you can handle this one, a couple years ago I had a polyp on my vocal cord and it required surgery.

Stephen Calabria: Like a Julie Andrews situation.

Susan Baum: I don't know what caused hers. Mine was from coughing. I'd been helping a friend of mine clear out her cousin's moldy house, and I coughed myself into a polyp, which was upsetting, but you could just see that little sucker on the [00:31:00] scope.

And I had a wonderful surgeon and I was on total vocal rest for a few weeks and I had a big whiteboard, a dry erase whiteboard that I was using in my lessons to teach and I had a friend who was in the hospital and I was communicating with the doctors with old-fashioned pad and pen.

And the doctor told me that I could resume normal activity. And she said, because you're a teacher, I trust you to know how much is enough every day while you heal. And I could tell after doing one of my exercises that, that was enough.

That was enough for that day. And I said, and I just took my dime and, so I've pulled myself back from other challenges.

And, having this diagnosis one step at a time, you faced other challenges, you can handle this one. And again, it's not a life threatening [00:32:00] challenge. I admire people who have potentially terminal illnesses. That's a whole other ball game.

This is not that, but still it is your life. It's your life. And what makes one person carry on where another person says, I can't do that. It's too much, because it is a lot to take on, and I said, no I'm there. I'm just gonna go ahead and do it.

And right now the therapy is not covered by insurance. So there's also a financial component to it about a challenge. I've written to my insurance company about it and giving them all the research and everything.

Say, you guys should check this out, so you just do what you can. That's how I feel about it and I remember that day sitting [00:33:00] in the doctor's office. He was sitting right over there and saying, oh God, here we go. It finally happened.

Stephen Calabria: Finally, for others listening who may be facing AMD or another hereditary condition, what would you want to convey?

Susan Baum: The more you know, the better off you'll be. The more you educate yourself, the better choices you'll be able to make.

When we had our initial conversation, you were talking about the chief component of resilience that you had heard about from people was a support system, and I feel very fortunate in that I have a wonderful family.

I have wonderful clients and friends, and I know I can count on them if I need [00:34:00] help. I've had clients come and help me paint a new studio in the middle of the night because I had to move from one to another.

People like that who will show up for you, and I think that's a big deal. But even do the research. See what's out there. Reach out to anybody who might have information that could be helpful to you. I went to the NIH website like frequently.

There's a lot of information out there, stuff that you wouldn't hear about in the papers because unless you're reading science journals, it's not gonna be there in the general press, anything.

I didn't find out about Dr. Rosen by reading Time Magazine, I found out because I was doing deep dive into the medical journals. There's a lot of good stuff out there. I was happy and pleased the way my retina [00:35:00] doctor, when he says, it's time for you to go see Dr. Rosen.

He said, congratulations, you really advocated for yourself? I said, yeah, I did. I don't quite know how else to do this except to keep going. It's, what was it they say failure is not an option. I, I think that's a good motto. Failure is not an option, and fortunately what I have is not painful.

I'm not in pain. That I think makes a huge difference. The emotional pain is something else altogether, but I'm not in physical pain. And I think for anybody who is God love you, but get as much information.

Reach out to as many people as you can find out about. There's new frontiers everywhere. This is a very exciting time for medical research. Not withstanding the political client. [00:36:00] There are people climate, there are people doing work that's really good and they intend for it to help as many people as they can.

Stephen Calabria: That's it for my questions. Was there anything else you wanted to say?

Susan Baum: I would like to thank Dr. Rosen, Dr. Richard Rosen. He is a wonderful doctor and. His work has made a huge difference in my life. Just this year, I'm looking forward to being his collaborator going forward.

All the staff over at the New York Eye and Ear Infirmary, they are totally professional, really kind. I love them dearly and I look forward to being a collaborator with them as well for the foreseeable future.

Stephen Calabria: Susan Baum, thank you so much for coming on Road to Resilience.

Susan Baum: Thank you for having me.

Stephen Calabria: Thanks again to Susan Baum for her [00:37:00] time and her story.

That's all for this episode of Road to Resilience. If you enjoyed it, please rate review and subscribe to our podcast on your favorite podcast platform. Want to get in touch with the show or suggest an idea for a future episode? Email us at podcasts@mountsinai.org.

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