SUSAN LOVE INTERVIEW MAKERS: WOMEN WHO MAKE AMERICA KUNHARDT FILM FOUNDATION

Susan Love Surgeon & Activist 6/24/2011 Interviewed by Beth Osisek Total Running Time: 53 minutes and 37 seconds

START TC: 00:00:00:00

ON SCREEN TEXT: Makers: Women Who Make America Kunhardt Film Foundation

Susan Love Surgeon & Activist

00:00:06:00

BETH OSISEK:

You were the oldest of five children. What role did you play in your family growing up?

00:00:12:00

SUSAN LOVE:

Well I was the oldest of five children in a good Irish Catholic family in New Jersey, and so that gives you a particular role of really being the ultimate big

sister. I mean, you have to help all your siblings, you have to move them along. My baby sister is 12 years younger than I am so in some ways I helped raise her, because by then my mother was tired of it. So it really puts you in a particular mode of being— of that role of being a big sister, which I think is still the sort of persona that I, I do with, with my patients and with other people that I work with.

00:00:51:00

BETH OSISEK:

In childhood did you more closely identify with your father or your mother? And why?

00:00:56:00

SUSAN LOVE:

I definitely identified more with my father. My mother was very into appearances and how everything looked and I was much more into studying and reading and books, and we didn't get— we fought a lot, didn't get along. My dad always wanted to be a doctor and I'm sure that— and he didn't and he didn't go to college, but I'm sure that that influenced me in my ultimate choices.

00:01:23:00

BETH OSISEK:

Did you ever question 0r defy your parents? Or were you more of a pleaser kind of rule follower growing up?

00:01:32:00

SUSAN LOVE:

I was raised in a, in a strong Irish Catholic family and I must say I was very much of a, of a follow the rules and pleaser and trying to be what everybody wanted me to be, whether it was at school or at home. So I wasn't very rebellious then. I've certainly turned around a lot as I got older, but I put in my time as a good girl.

00:01:57:00

BETH OSISEK:

You often refer to yourself as an outsider. Did this start when you were young?

00:02:02:00

SUSAN LOVE:

When I was 12 years old we moved from New Jersey to Puerto Rico. And, because of my father's job and went to, I went to a Catholic school in Puerto Rico and I was the only primary English speaker in my class. So everybody else had been raised in Puerto Rico and spoke primarily Spanish. The classes were taught in English, but the gossip was in Spanish and the playground was in Spanish, and I—

00:02:31:00

That was, in some ways, I think the beginning of feeling— and culturally I was certainly an outsider. I came down from New Jersey doing the twist, and they thought I was a loose woman and I was 12 years old. I didn't know any better. So, that was the first time I really felt like I didn't quite fit in and I was an outsider. And, and then that role continued because we moved after 3 years

to Mexico and then... then when I came back to go to college I had all this experience living elsewhere that the other people in college didn't have. So, it was really in middle school that I became, became obviously an outsider.

00:03:09:00

BETH OSISEK:

What was the first experience you remember standing up and fighting for as a child? Or was there one?

00:03:16:00

SUSAN LOVE:

When I was in high school, I was part of the Newman club. I went— this was in Mexico City now. And I was in the American school and we met once a week and they were going to take away our social hour. And we actually picketed the church to get our social hour and our refreshments back at our weekly meetings. So that's the first time I really remember standing up to authority and saying, "No, you can't do it that way."

00:03:42:00

BETH OSISEK:

And what was that like for you as a good Catholic girl who obeyed the rules?

00:03:46:00

SUSAN LOVE:

It was very... it was very exciting to be able to break through the rules andand rebel against authority in that way. Although, I must admit in hindsight I understand what they were trying to do because not everybody could afford

to provide all the refreshments. But we certainly felt that this was an important issue.

00:04:07:00

BETH OSISEK:

Did you always want to be a surgeon?

00:04:10:00

SUSAN LOVE:

I always wanted to be a doctor. I liked science a lot and I liked taking care of people. Or-or-or doing things with people. So the idea of becoming a physician came very early on when I was still in high school. I did not think about being a surgeon early on. In fact, we thought surgeons were plumbers, which is how they were referred to in medical school. But when you're in medical school you rotate on every different specialty, and surgery was the one that was the most appealing because with surgery you could actually cure people.

00:04:43:00

If you take their appendix out they never get appendicitis again. Now whereas if you're treating somebody with diabetes they are going to have diabetes the rest of their life and you're just sort of helping them along. And I really liked the immediacy of going in and fixing something and using my hands to do it. And so that's what really led me into surgery.

00:05:01:00

BETH OSISEK:

Now, I read somewhere that you had joined a convent at one point. That's a very divergent path from the one that you ended up on. Can you talk about that a little bit?

00:05:11:00

SUSAN LOVE:

Well...Let me think where to start. When I was in middle school we lived in Puerto Rico and I went to a Catholic school for the first time, and all the other students were primary Spanish speakers and I was the only state side English speaker in the class. But the nuns were all from the States. And they all were young in their early 20s and very zippy. So I, I really affiliated more with them than I did with my classmates who were of a different cultural background than I was.

00:05:45:00

And so that idea sort of got in my head. And when you're raised Catholic, you always sort of get this idea. And they say if you even think about the idea of becoming a nun, that's God tapping you on the shoulder and telling you that maybe you should do it. So I kept it in mind and then half way through college I went and joined the school sisters of Notre Dame in Connecticut, and it was an interesting time. It was right after Vatican II. There were lots of changes happening. And nobody quite knew what was going on. And so it was a, it was actually also a difficult time to go into the convent because the old...they didn't want to do the old rules, but they hadn't figured out the new rules yet. And they sent me to Fordham because I already had two years of college. And

I lasted about nine months, so it was not a long career, and then I kicked the habit and went, continued at Fordham, outside of the convent.

00:06:39:00

BETH OSISEK:

How did you get from the convent and Fordham into the medical field?

00:06:45:00

SUSAN LOVE:

I never left the idea of becoming a doctor even when I was a nun. So I had told them I wanted to be pre med. And they let me stay pre med and they decided I would be a doctor and take care of the old sick nuns or something. But they were supportive of that. So I just continued on that pre med pathway once I left the convent. And, you know, I applied to medical school.

00:07:09:00

BETH OSISEK:

It sounds like you were an amazing student, so I imagine you must have had your pick of medical schools.

00:07:15:00

SUSAN LOVE:

Not quite. You know, this was the days when there were still quotas in medical schools. And I finally got into Downstate, which is in Brooklyn, and Georgetown. I went to Downstate because I was paying out of my own pocket and it was a state school. But half way through medical school, Title IX came through.

00:07:34:00

BETH OSISEK:

So did that impact you specifically at all?

00:07:37:00

SUSAN LOVE:

Title IX impacted me in the sense that by the time I was applying for a residency program, all the training programs wanted a token woman, and there were very few of us because we had been part of the quota class. So there were not that many of us graduating from medical schools. So for those couple of years you, you started to have a better position being a woman and applying to be a resident than you had previously.

00:08:04:00

BETH OSISEK:

Did your rejections from medical school make you at all rethink your career choice?

00:08:10:00

SUSAN LOVE:

Once I decided I was going to be a doctor and once I was at that point in my career, I was bound and determined I would show them and I would do it and nothing was going to get in my way. So my re—the initial rejections, I was just going to go into the Peace Corps and then come back and do it again. And it did–just didn't really occur to me that anybody could stop me.

00:08:34:00

BETH OSISEK:

Why were women discouraged from the medical field and specifically surgery at that time?

00:08:40:00

SUSAN LOVE:

At that time there were no women, very few women doctors and almost no women surgeons. And in fact my pre-med advisor at Fordham said to me that if I went to medical school I would be killing some boy because he would have to go to Vietnam. So if— and I would take his place. He'd go to Vietnam and he'd die and it would be all my fault. So there was really no encouragement for women to go. And it really was felt that people really acted as if you're going to take somebody else's place that would be much more deserving. And you're just going to get the education and then you're going to stay home and have babies and it will be totally wasted.

00:09:22:00

BETH OSISEK:

You touch on this a bit, but can you talk again specifically about why you picked surgery? Addressing the fact that this was a typical choice of the female doctors at that time.

00:09:33:00

SUSAN LOVE:

The women who were in medicine often took the easy way out and– and became gynecologists or pediatricians. That was— it was sort of well maybe you can do kids or other women, but god forbid you should get near men. so surgery was not a popular choice. And If you really wanted to do surgery you

probably did again gynecology where you could, you were just cutting on women. But, but I was determined. I wanted to be a surgeon. I went to the chief of surgery at the time who was an African American. And he said, "Well, did you fail surgery?" And I said, "No, actually I did quite well and I want to be a surgeon."

00:10:08:00

And he said, "No woman can ever be a surgeon in my program." And this was again the person who was writing my recommendation for the next step. So there was a very strong prejudice against it. I was actually the second woman at Beth Israel Hospital in Boston to go through the program. And the first general surgeon woman on the staff of Beth Israel hospital in Boston when I finished. So it wasn't, you know, there just wasn't a lot of people ahead of us that you could model on, and it was, it was difficult and there was a lot of problems.

00:10:41:00

SUSAN LOVE:

I don't know why he thought that I couldn't. What's the basis of sexism after all? It's just a, you know, unfounded prejudice and–and obviously those unfathomed prejudices were rampant. It just wasn't in people's mind set that you could even have women surgeons. For example, when I was in practice and I was covering for my partner, I went in one time to see a patient over the weekend and after I left the woman said, "You know, that Dr. Goldman is so nice. When he can't come in he sends his wife instead." It was just amazing. Or another time I went in to see an elderly man and decide whether he needed

surgery. And I did a whole evaluation. I decided he didn't need it. And then as I was turning around, and this was somebody in his 80s, he took his hand and just ran it down my butt and down my leg. And I turned around and I said, "Oh, I forgot to check your prostate."

00:11:33:00

BETH OSISEK:

Was it your intention to focus on women's health?

00:11:36:00

SUSAN LOVE:

I wanted to be a general surgeon and when I finished as chief resident, I said they are not going to make me into a breast surgeon because I can do those big operations just with the best of them. I can do macho surgery. I have done it all and I can do it. And at that time breast surgery was really thought of as sort of wimpy. The people who did breast surgery were the ones who were on the verge of retirement or they weren't that good. So we'll throw them the bone of breast surgery.

00:12:04:00

And I was determined I wasn't going to let that happen. I finished and I was there at Harvard hospital, but nobody offered me a job. There were no academic jobs, no job offers. All the guys were getting all these offers because nobody wanted a woman, and so I opened a practice and nobody sent me any patients. The only patients they sent me was– were women with breast problems because they thought maybe that– the women will like that.

00:12:34:00

And it became very clear to me, very quickly, that women were not being very well treated. It was still the days of don't worry dear, I'll take care of you and you didn't know what was going on or how you were going to wake up or what the story was. And so, just by talking to women and educating them and telling them what we were going to do, why we were going to do it, made a huge difference. It was also just the beginning of the data that showed you could do less than a mastectomy. That in Italy they were doing lumpectomy and radiation. And they had data showing it worked just as well. But in America the surgeons said, "That's Italian women with Italian breast cancer. It won't work in this country." So it was a very interesting time in breast and turned– and it soon became apparent to me that what started as a career really was going to be a mission.

00:13:25:00

BETH OSISEK:

What was it like being a breast cancer patient at the beginning of that time for you?

00:13:31:00

SUSAN LOVE:

The very beginning of it, there were still a lot of people who were having one stage operations, which meant you needed a biopsy. You went into the operating room and if it was cancer they did an immediate mastectomy. Now afterwards, the only way you knew whether you had cancer was actually by looking at the clock because by the time you woke up from anesthesia, the surgeon was gone, the nurses weren't going to tell you. And you had a

bandage on either way. So if it was one hour it was benign and if it was 3 hours it was mastectomy, and that– and in those days in order for reach to recovery, which brought the prosthesis into the room in order for them to see you, you needed the doctor's permission.

00:14:12:00

Because he would decide whether you could handle seeing somebody else who had breast cancer talking to you. So everything was still controlled really pretty much totally by men, you know, by their–by husbands. It would be what, "well what does your husband think you should do?" kind of thing and women really had no agency and no say in the matter, even though this was an issue that was really obviously close to, to their hearts.

00:14:39:00

BETH OSISEK:

And do any patient stories sort of stand out in mind for you?

00:14:42:00

SUSAN LOVE:

There was one judge in Boston early on. And she was– and who came over. She had been seen at Mass General and then she came over and saw me. And she had a lump and we ended up doing a lumpectomy and– and radiation. She did fine. But in– when she was seen by the doctor at Mass General he said to her, "Well there's no ovary and no breast so good that we should leave it on." And she just got up and walked out. But she got a lot of grief for coming across— Here was this young hotshot woman surgeon and, and the male

surgeons really did not like me at all. And they couldn't figure out what I was doing differently than what they did.

00:15:21:00

So, they would send groups over to visit the breast center that we had. And they decided it was the mauve carpet. And to this day you'll notice most breast centers have mauve carpets, but they couldn't understand that it was, that we were actually teaching women as, like intelligent human beings and explaining things to them and giving them some choice in the matter. That was it just was totally not in their experience and it was not in their education, and they couldn't figure it out.

00:15:49:00

BETH OSISEK:

Have you ever been daunted by this battle?

00:15:54:00

SUSAN LOVE:

I can't let myself be daunted by this battle. I– I really feel that if we, if we just focus on the right way, we can find what causes breast cancer and we can stop it. And what frustrates me more is that we've raised lots of money. And, and worn lots of pink, and done lots of walking and running and all the rest of that. And yet we're still treating it the same way that I did years ago. Surgery, radiation, chemo, hormones. And we never subtract anything, we just add more treatments. And they all have collateral damage. And what we really need to do is figure out the cause.

00:16:32:00

When you think about cancer of the cervix in my professional career, we went from doing a total hysterectomy if you had an abnormal PAP smear and where you lost your fertility to now giving a vaccine and preventing it altogether. Now when is the last time you saw a march or a walk for cancer of the cervix or even a ribbon? And yet we have the answer. So what are we doing wrong in cancer of the breast? I think one of the things is we're victims of our own success. We've raised so much money that it hasn't been very well spent that there's no urgency to focus it because we know that there's a lot of it out there.

00:17:08:00

And the drive to finding the– the cause has been deemed too difficult, and so we focus on little things. And then the last thing is we really do a lot of the research on rats and mice. Now rats and mice don't get breast cancer. Women are, and domesticated dogs, non spayed domesticated dogs are the only animals that get breast cancer. So we have to give it to rats and mice in order to study it.

00:17:36:00

If you don't do the research on women you're not going to figure it out. In cancer of the cervix they have to do the research on women because it was human papilloma virus. Not rat papilloma virus. And I mean you can see the rats sitting up in stirrups. It would be difficult anyway. But really you had to do it on people. So now my focus is really to get women involved and to get researchers to refocus on women and to find the cause because if we can end cancer of the cervix, there's no reason we can't end cancer to the breast.

00:18:10:00

BETH OSISEK:

Who does medical research, in general terms, focus on and why?

00:18:15:00

SUSAN LOVE:

The problem with medical research is it no longer connects as much as it should to patient problems. In the old days, you were a doctor scientist. So you went from the patient and said this is the problem. Then you went to the lab to figure it out, then you came back. People like Louis Pasteur and all those guys were back and forth. Now it's too hard to do that. Medicine is too complicated and science is too complicated.

00:18:41:00

So what happens, though, is then you do the science based on what's interesting to scientists or what new tool you have, and it's— and then you look for a clinical application to it. And that doesn't work very well. What we really need is more translation. And when they talk about translational research they usually mean bench to bedside. But we need bedside to bench, too. We need to make the scientists be focused on the problems that we are seeing in the clink, if we are going to get the right answers. Otherwise, it's just very interesting science, but we haven't fi–, and they say maybe someday this will be the answer to cancer. But that someday often doesn't come.

00:19:23:00

BETH OSISEK:

Are most research studies focused one sex as opposed to the other?

00:19:28:00

SUSAN LOVE:

When we first started doing, you know, when I first started this– my career, there was really very little research on women's health and very little research on women. And the breast cancer advocacy movement, which really started in the early 1990s, one of our biggest goals was to increase the funding. And indeed we did that. So it went from about 40 million to 300 million in a year. Now breast cancer research is very well funded, and so we really can't complain about that.

00:19:56:00

But what we can complain about is that it's not very well directed and it's not focused on really let's stop the disease altogether. I don't think the scientists or the funders are maliciously doing that. I just think that it's easier to think well let's just see if we can get another drug. And you can get pharmaceutical funding for that. Or let's just see if we can figure out how this cell actually works, rather than the bigger question of what starts this in the first place and how can we stop it?

00:20:26:00

BETH OSISEK:

So it's sort of systemic then?

00:20:28:00

SUSAN LOVE:

It's very systemic. What happens is you get your PhD and you want to cure cancer. But you realize you have to get tenure. And in order to get tenure you

need to get a lot of grants, you need to publish. And so you have to— you can't do something too big. You need a little thing that you'll be able to finish. So you do that. You need a little thing that you're going to be able to finish so you do that. And you can't be too wild because there's peer review, so other scientists are looking at it and if it's too out there they're not going to agree that you should be funded.

00:20:54:00

So you do a little iterative thing that's just a little bit different than your professor and you do it in rats cause they're quicker and easier. You can buy them and you can control them. And then you do another iterative thing. And then by the time you get tenure you forget that you were going to cure cancer. And then you're part of the system. So the system is really not set up to do big questions or to really look at big new ways of thinking about it. It's really set up just to perpetuate itself.

00:21:20:00

BETH OSISEK:

Also, you hit upon something else, which is it doesn't reward renegade thinking. Most of these cures come from out of the box thinking, so can you address that a bit, too?

00:21:31:00

SUSAN LOVE:

And, you know, the system the way it's set up sounds right. You want to have other scientists reviewing and making sure it's worthwhile data, but what happens is they're also threatened by far out ideas. And so, you don't get

funded if you have far out ideas. You don't get money to do it and you don't get the support to do it. And so it's very difficult to break out of the status quo and to really think differently.

00:21:58:00

BETH OSISEK:

Now how are you trying to up end that?

00:22:00:00

SUSAN LOVE:

One of the things that we're trying to do is we, first of all we do our own research here at the Dr. Susan Love research foundation. And so we're trying to— the things that I can't find anybody else to study, I just do it myself and we get, we try to get funding wherever we can snag it. So with breast cancer, for example, there is a lot of emphasis on understanding the cancer and how does the cancer work and do cells? And there's almost nothing on the breast.

00:22:29:00

So here you've got this organ. We are the only animal that has our breasts at the ready all the time. You think about it, dogs and cats and all other mammals are flat chested and then they have their babies and their breasts come out and they feed them and then they go flat chested again. So we, we're there, our ducts are suspended in fibrous tissue and yet nobody is studying it. We know more about the molecular pathways of a cancer cell and we're still arguing how many holes there are in the nipple because nobody has worked out the anatomy of the breast ducts.

00:23:00:00

The breast makes blood into milk. That's really pretty magical when you think about it. What's it doing when it's not making milk? Which is most of our lives. We have no idea. We have no idea of what gets into the fluid, what doesn't get into the fluid. Nobody has ever studied it. So we're trying to understand what the normal breast does as a... so that we can figure out why does cancer start there, and how can we change that or change the conditions in order to prevent that from happening in the first place? But if you start with the cancer, it's a little bit like starting at, at, on death row and interviewing criminals as to how they got into crime instead of going to the high schools and talking to the troubled kids when you can actually figure out what the early conditions are.

00:23:46:00

BETH OSISEK:

What made you decide to write Dr. Susan Love's Breast Book (1995)?

00:23:50:00

SUSAN LOVE:

Once I decided and recognized that I was going to be dedicating my life to treating and taking care of people with breast cancer, I got pretty good at explaining how we thought about breast cancer and how– why there were different choices. We had been talking and in those days about how the breast cancer diagnosis was an emergency. And you had to immediately rush in and cut the whole breast off, and the more you could do the better. And it was really understanding that it didn't go that way, and that some cancers

had already spread and some hadn't that that changed our approach, clinically.

00:24:26:00

But patients weren't being told that. So here we had been telling them one thing all these years and now we were giving them a different treatment. And they were totally confused. And I worked out how to explain it, what are, what analogies to use. How to make it understandable. And I realized that I really should get it out there, and so I– I wrote *Dr. Susan Love's Breast Book*, which is really not very fat in those days, I must admit. And it immediately, it was the first book that actually explained the science.

00:24:55:00

So the other books out there about breast cancer were why me or oh this terrible thing happened or how I coped. And they were useful, but they didn't tell people what they needed to make. And that was what the breast book did. Doctors hated it. The doctors really didn't like the breast book. And patients would say to me they would walk in holding it and if the doctor turned pale they would leave and go to another doctor. But it was the one of the first books that actually explained, you know,--

00:25:24:00

- you weren't supposed to tell, you weren't supposed to give people the magic. You weren't supposed to tell them what we were thinking or what we knew and didn't know. You were just supposed to pontificate in those days.
And so actually making the patient a participant in the process was very new and very scary to the medical profession.

00:25:42:00

BETH OSISEK:

So you empowered these patients then.

00:25:45:00

SUSAN LOVE:

I empowered the patients and I gave them the information they needed so when they— You know, I had said when I wrote the book I want if you get diagnosed with an abnormal mammogram on Friday, I want you to be able to get this book read about it. And when you go into the doctor on Monday you feel like you know what questions to ask. You feel like you know what are the things you need to know. And–and indeed it has enabled people to do that. I do it every five years. I rewrite it from scratch because everything has changed and the fifth edition came out in 2010.

00:26:21:00

BETH OSISEK:

I read one very old review, though, in which a doctor said that a little bit of knowledge was dangerous for these patients.

00:26:27:00

SUSAN LOVE:

Absolutely. Doctors felt very strongly that– that having the patients know too much was bad and that if the patients found out that we didn't know the answers, that would be terrible. That would be detrimental. And those were still the days when often you didn't even tell people they had cancer. Oh we did a mastectomy, but you didn't have cancer. It just was a lot of junk in your

breast and we thought it would be safer, things like that. It was amazing, the paternalism. And I can't say maternalism cause there weren't any women, but the paternalism was really unbelievable.

00:27:03:00

BETH OSISEK:

How do you feel about telling people in power positions or of the establishment they are wrong?

00:27:11:00

SUSAN LOVE:

You know, because as a woman surgeon, when there were no women surgeons, and then as a lesbian woman surgeon it was really very freeing because it was very clear I was never going to be chief of surgery at Mass General. That I was never going to make it in– in the traditional medical world. And so that was very freeing. That meant I had nothing to lose. And I could say my truth and I could say the truth for the patients, and there was no position I was going to lose because I wasn't going to get it in the first place.

00:27:42:00

And I think if I had been a white male in the same position, you are much more reticent to point out what you think is wrong and what you think is right. And so that– that power that really came from being an outsider is what enabled me to be able to say, "You know, that's not right." Or "It doesn't make sense," or "It doesn't follow," and certainly I've gotten a lot of flak for that. I think that you need to have a certain personality. I read somewhere

that iconoclasts in general tend to have— not mind criticism as much as other people.

00:28:20:00

And you certainly have to be able to do that. When I stood up against hormone replacement therapy I got a lot, a lot of flak. And when I was out there saying we could do breast conservation, people said that I was killing women. But I, but there was data, there was always science behind what I was saying, and so I felt secure in my position and I did it. One of my colleagues said that always described me as the person in *The Emperor's New Clothes*, who has no clothes and said, "I think he's naked." And, and that's a role I sort of relish.

00:28:56:00

BETH OSISEK:

Are there people that really resonated with you over the years?

00:29:00:00

SUSAN LOVE:

Well, you know, I do have particular patients both of mine and other women that I've met along the battle. So one is– is a neighbor across the street from us. Mother of six kids, was pregnant with her sixth kid when she was diagnosed with breast cancer. And ultimately died of it. And I told her before her daughters grew up, I would get rid of breast cancer. And every day when I drive home and park in my garage, their house is right across the street, I am reminded that I have this sacred duty to do that for her.

00:29:33:00

There are other people. Somebody who was an advocate with us who wasn't a patient of mine, but who had, who died recently and she had had early breast cancer, had a lumpectomy and radiation, was fine. And 20 years later she developed cancer caused by the radiation. And ended up dying of it. And that to me reminds me of why we've got to find the cause of breast cancer because the treatment has collateral damage. The treatment can kill you. And so the goal is not the cure. The goal has to be the cause and stopping it.

00:30:09:00

BETH OSISEK:

With a woman that has so many accomplishments, what's left for you?

00:30:15:00

SUSAN LOVE:

I still have a lot of work to do because we don't know the cause for breast cancer. I have a lot of work to do to reorient medicine into– into actually answering the right questions. I think that the answer to breast cancer could be as simple as, you know, HPV is to cancer of the cervix. But we have to look. The majority of women who get breast cancer have no risk factors. They did everything right and they still got it. So we're missing something really big and what we're trying to do now, since I have hard time convincing the scientists to change direction, is I am using, you know, emboldening the women to take it on.

00:30:53:00

So we have an army of women we're recruiting. Of women who are willing to participate in studies. And we have 356,000 women right now. 80% of them

48 Wheeler Ave, 3rd Floor Pleasantville, NY 10570 T 914-238-6800 kunhardtfilmfoundation.org

25

have never had breast cancer. They sign up. We give them, scientists come to us with their studies. We e-blast everybody and then we don't match them because you might not fit a study or another woman might not fit a study, but her neighbor might or her daughter might or her sister in Indianapolis might.

00:31:21:00

And so we have already put 50,000 women on studies and that's going to accelerate the process. If we can make everything move faster so we can test hypotheses and say this one doesn't work and go on to the next one, we'll get there. We're about to start a long term study where we're going to track women and really look at things that haven't been looked at. So not just the same old risk factors that we always talk about, but the other things: Environmental issues, could they be related?

00:31:50:00

Could there be other lifestyle issues that we haven't thought about yet that are related? I was meeting with a– a potential colleague and we're going to start looking at what bacteria live in the breast. Nobody's looked at that. We know bacteria cause cancer of the stomach. Makes sense they could cause cancer of the breast, but we got to look. So it's always trying to push ahead and think we can do it. I think we can be the generation that stops breast cancer, and that's what drives me. I really, I really feel deeply that as a good catholic girl this was the mission I was given. This is my–my role in this life and, and I'm going to do it if it kills me.

00:32:39:00

BETH OSISEK:

What were your expectations about love and marriage? And how did that all turn out?

00:32:36:00

SUSAN LOVE:

I was raised in a traditional family and I certainly assumed that I would find a husband and get married, and when I finished my surgical training, I dated guys in high school and college. And when I finished my surgical training and started in practice I said ok so now it's time to find a man and settle down. And I went on a find a man campaign. And with another woman and we put ads in the Phoenix newspaper in Boston. And we found a man. In fact, the same man.

00:33:10:00

He, I think, he answered my ad and she answered his ad or something like that, but and then it suddenly I realized I was actually more interested in her than I was in him. Now she wasn't interested, but that was the beginning of my thinking, I really had not even realized that being a lesbian was on the menu, that it was something you could, that you could choose or be until that time. And it was shortly thereafter my wife Helen actually was a resident at Beth Israel.

00:33:42:00

She's a surgeon also and I knew she was gay. She had been involved with women before. And I thought she was very scary. Actually, I thought it might be catching, I think unconsciously. And so she would be coming down the hallway and I'd run down the back staircase. And I was right. It was catching.

We went up Labor day weekend— She asked me if I wanted to go. She had a place up in the mountains. And, and she was just bored and looking for companionship. And I went with her and we fell in love Labor day weekend and we've now been together 28 years, um, since then. And so once, once I realized and once I had that really I could be involved with a woman and found a woman, you know, I was set. A few weeks later or a few months later I was actually there was an article about me in the Boston Globe and I came out in the Boston Globe and I was out. That was it.

00:34:37:00

BETH OSISEK:

Did being outed so early make the fight easier?

00:34:42:00

SUSAN LOVE:

It was... You know, I'm just the kind of person that what you see is what you get, so I'm not a good secrety hiding person. So I was so happy to be in love that I was telling everybody and we invited the chief of surgery over for dinner at her house 'cause we figured that way nobody could go to him and say, "Oh, did you know?" because he had already been there. And, and so it— I, I was out in the Boston Globe and I didn't noticeably lose any patients. In fact, I had some good experiences as a result. One young woman wrote me from Rhode Island. She was in high school. She had just come out and she had always wanted to be a doctor and her parents thought oh now she can't be a doctor and she showed her, her parents the article, and thanked me for being out in this article.

00:35:28:00

And the irony is years later I was at Columbia University giving a talk and this woman came up to me and she was the chief resident in surgery, and it was that woman from Rhode Island who had come out around the same time as I was in the paper. And another patient of mine's son had been— She was an Italian woman from east Boston. An older woman just the kind that you would stereotypically think would be appalled to have a lesbian doctor. And she said, "I've got to talk to you. You've done the most wonderful thing."

00:35:56:00

So after the exam she came into my office and she said, "You gave me my son back." And it turned out her son was gay and lived in California and she sent him the article, and when he realized that his mother went to a gay doctor, he was able to— he flew home and they were reunited and she was so grateful. So I've actually only had good experiences. I mean I don't know what people say behind my back, but that doesn't bother me. And I feel like living out loud really allows you to be who you are and– and to get into the work you need to do as opposed to spending a lot of time trying to protect yourself.

00:36:34:00

BETH OSISEK:

You were a ground breaker, well you and your wife were groundbreakers, on the adoption front as well, setting new legal precedent. Can you talk about that?

00:36:44:00

SUSAN LOVE:

After Helen and I got together we wanted to have a kid, and so this was early days. I mean now it's fairly common, but there weren't that many people gay and lesbian couples doing it and we– we I had Katie. Her dad is Helen's first cousin and so she's related to both of us, and everything seemed to be fine. And we went on a trip to Mexico where my family was and they... the people at the airlines said, "Well, do you have permission from her father to let her leave the country?" And we said, "what?" You know, "we don't need permission from her father." Her father's not involved in her, in her upbringing every day.

00:37:28:00

And so that made us realize that we really didn't have the rights that we needed to have. So we came back and we sued that I had all the rights as a birth mother, but Helen had none. That Helen would be able to adopt Kate. Initially, they wouldn't even take the case. Then we had to sue for them to take the case. They took the case and then they had– we had to have a lawyer for Kate and a social worker. She was 2. And a psychiatrist for her. And we had to put on this prima facie case in Boston.

00:38:00

It was touch and go. All of my, my dad flew in and my brother and all our male relatives flew in and testified as to what great parents we were. And then the– the case ended up the judge agreed that it was in the best interest of– of the kid, but kicked it up to the appeals court. By then we were moving to California. I had been recruited to come out to UCLA, and so we had to debate

and all the gay and lesbian lawyers were debating should we go forward or not because in California we could do it.

00:38:33:00

And they finally decided we were their best shot in Massachusetts, and it was not a really liberal time in Massachusetts. They had just taken some foster kids away from 2 gay guys and there was a lot of homophobia going on. And so we did it. we put the case forward and, and in order, the way the law is in Massachusetts, in order for Helen to adopt Kate, I had to give up my rights as a birth parent, and then we had to adopt her together. That's how they do second parent adoption.

00:39:02:00

So we, I was flying out to Boston to give a talk. Helen and Kate preceded me when they actually announced the– the results and it was close. I forget it was 5 to 4 or 4 to 3, but it was a very close decision in our favor and it was just wonderful. So we changed the birth certificate in Massachusetts and we actually feel that it might have led, made it easier for gay marriage in Massachusetts because by the time they did marriage, they had had ten years of allowing same sex couples to adopt. We used to... there was a period in the early days where we'd suddenly get flowers delivered to the house in California or from somebody in Boston who had been able to adopt their kids.

00:39:44:00

BETH OSISEK:

Why was being a mother and having a child important to both of you when you had such amazing careers?

48 Wheeler Ave, 3rd Floor Pleasantville, NY 10570 T 914-238-6800 kunhardtfilmfoundation.org

31

00:39:49:00

SUSAN LOVE:

I must admit it's Helen who really wanted us to have a child. She is one of two. I am the oldest of five. I sort of felt like I had already done that with all my younger siblings. And so I didn't feel quite as pressured as she did. But she tried to get pregnant first and didn't get pregnant so we switched. And being Irish Catholic of course I got pregnant right away. And– and so I'm so glad because it's been such an important part of, and remains such an important part of my life and I'm so glad I didn't miss that experience of– of parenting and really bringing up another person. It's been... I've grown so much in the experience and learned so much in the experience that it's been, it's just been an enormous gift.

00:40:32:00

BETH OSISEK:

How has it impacted your work?

00:40:35:00

SUSAN LOVE:

Having a– having a child and particularly having a girl really makes you realize even further that we have to be the generation that takes care of this problem. We can't just keep passing problems on to the next generation. For somebody else to do. This is our work. And we have to do it so that they can get on to the next thing, or the next disease, or the next problem. It doesn't have to be. We sort of get in this mind set that oh cancer has always been with

us. And breast cancer has always been with us and it runs in families. And it's got to be this way.

00:41:11:00

And it doesn't. There are lots of diseases we've stopped. Polio, you know, when I was a kid it was a big deal and now polio, really in this country is not a problem. You know, as I said, cancer of the cervix. My cousin had a hysterectomy for an abnormal PAP smear. My sister had a hysterectomy for HPV, and my daughter has been vaccinated. Say oh no, cancer of the cervix is just not something that's going to be in their menu, in their mindset. We can do that with cancer of the breast. There's no reason we can't do that and we have to do it. So having a daughter really makes me realize my responsibility and our generation's responsibility to stop it.

00:41:52:00

BETH OSISEK:

Do you think your daughter will grow up with different ideas about marriage than you did?

00:41:56:00

SUSAN LOVE:

Well I have been together with– with my partner for over 28 years, but we have been married for almost 3, not quite 3. We were in the California 8, well actually the first time when– when Vermont did civil unions we had a civil union in Vermont. Then when they had the illegal marriages in San Francisco, we eloped and went up to San Francisco and stood in line and got married. But that got nullified six months later. And then when they had the, the

California supreme court said we could get married. Two weeks later we did it.

00:42:28:00

We were in line the first day to get a marriage license because I didn't trust that window was going to be open for ever and– and we got married. So she, she, my daughter has been very part of our process of trying to have a marriage and a... and really it's both the legal, the legal rights. I would also, I actually would like to have a marriage in the church someday because I believe in sacraments and grace and all the rest of that stuff and I– I really think that that's important. But little by little. I would never have believed when I first came out that I would be able to marry my partner. And so it may still come.

00:43:18:00

BETH OSISEK:

Do you consider yourself a feminist? And what does that mean to you?

00:43:21:00

SUSAN LOVE:

I absolutely consider myself a feminist. I think that if we don't continue to fight for women's rights both here and around the world. Because we've made a lot of progress here. But there's really a lot of places when you look at how they can't drive. Women can't drive in Saudi Arabia. I mean that's just amazing. And we made this progress because of the really hard work of the generation before us. I was able to benefit from it in my career, really.

And, and we owe it to the, to the generation and the world to really support women and to fight the good fight for them, as well as for us.

00:44:03:00

BETH OSISEK:

How would you define the Women's Movement today?

00:44:06:00

SUSAN LOVE:

I think that the Women's Movement today is, it's interesting because I think that a lot of young women today when I tell them, for example, that there were quotas in medical school, they are horrified, they can't believe it. So they don't realize how far we've come and not very long. And they also don't realize how easily it can be taken away. And I think that's something I don't like to be an old curmudgeon, but you sort of feeling like saying, wait a minute you guys. This, this, this can disappear too.

00:44:37:00

And we have to continue to be vigilant and we have to fight not just for our ability to become lawyers and doctors and businessmen or business women, but also for everybody else to be able to, to benefit from that. So I do feel like the Women's Movement had lost some of its steam by a lot of the accomplishments. And– and we need to and maybe it's by–by invigorating the international movement, but we need to, to reinvigorate it and– and let these people realize that the fight isn't over.

00:45:14:00

BETH OSISEK:

What do you think is the biggest change for women in medicine since you entered the field in the 1970s?

00:45:19:00

SUSAN LOVE:

Since I entered the field in medicine, there are certainly a lot more women. it's about 50% now as opposed to the 5 or 10% when I did it. However, what's very interesting is not at the top. I mean there's one woman chief of surgery in the United States. That's it... At an academic institution. That, that as in as often happens, there's a lot of women at the lower echelons and then as you start moving up to the higher positions, the women aren't there.

00:45:52:00

The same way they're not in the boardrooms and the same way that there, there are less of them that are CEOs. So I think we have to be careful not to say oh well more women are going into medicine and that's enough. We have to continue to fight the battle. Now as the pipeline grows and as there are more women behind, then I think we will get more women at the top. I also think that having women in the field will change the field. I think already we are seeing that. That women approach patients differently than my generation.

00:46:25:00

I mean my generation was very interesting because– because the Vietnamese war was going on and men could get a deferment, a lot of men who were really smart who today would be hedge fund salesmen went into medicine. Because they didn't have to go to war and then they became, in some ways, I

think exploited the business of medicine. And we certainly have seen that in our fee for service system in this country. And I think as we get more women who would rather be employees, who would rather work in a team, we're going to see much less of the single practitioner or group practitioner trying to maximize income and much more of a let's maximize public health and let's look at it in a different way.

00:47:09:00

BETH OSISEK:

Has it changed enough?

00:47:11:00

SUSAN LOVE:

Medicine has definitely not changed enough. The system that we have in this country really doesn't work. People sometimes say oh yes but we have the best medical care in the world. We don't. If you're rich you get too much care. And you get over treatment and over testing that's not good for you, and if you're poor you don't get any care. But we don't have the happy medium. And we certainly don't have a floor so that everybody gets at least a basic level of healthcare, and then if you want to pay you can do some extra fancy stuff. But we don't have that at all.

00:47:44:00

And so I really hope we get a single party payer. I hope we have Medicare for all because I think that's the best way to raise the bar for everybody to make sure the rich aren't too treat– over treated, and the poor aren't under treated. And we're all getting the maximum public health for everybody.

00:48:01:00

BETH OSISEK:

What do you think will be the biggest challenge that faces the next generation of women in medicine?

00:48:06:00

SUSAN LOVE:

I think the biggest challenge in medicine and for women in medicine is to maintain it as a prestigious job to do. That what sometimes tends to happen is when you start getting paid less then the men abandon it and then there are more women and then it becomes less important. And so you look at teaching, and you look at nursing, and you look at all of the, the sort of women professions.

00:48:38:00

And so, I think it'll be interesting to see what happens as we get more women. Now that may be good and it may be bad, I don't know. But I think that's going to— there is going to be a shift. And as there is less money in medicine you're going to see a different kind of person going into medicine and you're going to see medicine be different. And, and hopefully better.

00:49:00:00

BETH OSISEK:

Do you think it's easier to be a woman or a man in today's world?

00:49:04:00

SUSAN LOVE:

I don't know whether it's easier to be a woman or a man in today's world. I think that it's hard to be a man too because in some ways there's all these expectations on you and you're— it's hard to break. It's hard to break out of that as it was for us as women to break out of our expectations. I think for women now it's also hard because on the one hand they feel like they, they're smart they go to good schools, they get a career, but then they also want to be there with their kids and they're torn between which they should do,--

00:49:36:00

-and so I don't think anybody is having an easy time of it right now. And I think if we had better social structures. If we had better day care. We had better support for families, it would be easier for both and better employment policies about that, it would be easier for both. And so I think it's a battle that we should be doing as a country and a society as a whole rather than a woman male issue.

00:50:02:00

BETH OSISEK:

You've established an army of women to help propel research to find a cause. Can you talk about that a little bit?

00:50:08:00

SUSAN LOVE:

I have recently become very frustrated that we're not making more progress in breast cancer. We've raised all this money, we've worn all this pink, we've marched, we've run and we're still doing the same old thing we did when we started. And there are still 40,000 women in this country dying of breast

cancer a year. So with all our screening we haven't, we haven't decreased the number of deaths, and so what we really need to do I think is refocus. We need to focus away from figuring out breast cancer and how the molecular biology is to figuring out what's the cause in the first place.

00:50:42:00

And to do that we need to do research on women. We can't do it on rats and mice and petri dishes. We need to actually look at the people who are getting it and figure out what is it that's helping them get it. Now when I go to scientists and I say, why are you doing research on rats and mice? Why don't you do this on women? A scientist actually said to me, "Because women are too messy. I can't control them. With rats and mice I control what they eat, I control what they do. I control their genes. It's nice, pretty science." And it is. It's nice, pretty science but it doesn't solve the problem because most of the things we find in the rats and mice don't translate. So the other thing he said was, "And I don't know how to find women anyway."

00:51:26:00

And I said well that I can solve. That I know how to do. And so the army of women, with the funding from Avon, is recruiting a million women around the country who are willing to put their bodies on the line, to participate in research. To find the answers. It's really a glorified email list. It sounds very fancy, but you sign up and we don't take a lot of information, and then scientists come to us with their research. We vet it and then we e-blast it out to everybody in the army.

00:51:59:00

We don't match because even though we have a study, for example, that needed breastfeeding women, we send it to the 80 year old woman, because she's not breastfeeding, but her granddaughter could be or her neighbor or somebody she knows in church. So every time we send an email out it gets virally sent out with all the connections that we have now. And we have done in 3 years we have 356,000 women signed up. 80% of them don't have breast cancer. So the majority of the women want to find the answer are willing to be in studies.

00:52:32:00

I mean we have women who have core biopsies who give blood. And when you say why are you doing this. And they say because my friend had chemo. This is nothing. Because I want to prevent this from being there for my daughter. So women are very altruistic. They are willing to do it. And if we have enough of them we will force the scientists to share, and we're going to do it.

00:52:55:00

BETH OSISEK:

What accomplishment are you most proud of and why?

00:52:57:00

SUSAN LOVE:

I am most– most proud of having and bringing up a really good kid. Who is now 23 and I'm very proud of her.

BETH OSISEK:

What is the most meaningful advice you received

00:53:11:00

SUSAN LOVE:

My father taught me and drummed into my head that you have to make the world a better place for having lived. And I have drummed it into my daughter's head as well, but that is what I live by, that my having been here in this world for this finite period of time, the world has to have been improved because of my presence.

END TC: 00:53:37:00