

Beat Breast Cancer Like a Boss

Moderated by

Ali Rogin, with Joan Lunden and Jill Kargman

National Webinar Transcript

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Presented by:



SHARSHERET[®]
The Jewish Breast & Ovarian Cancer Community

This program has been dedicated by

the friends and family of Lisa Tselikidis Strobel and Laura T. Fine,
in honor of their mother,
Adele R. Selik z"l

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Melissa:

I want to thank everyone for joining us tonight for Sharsheret's second book club program. I am pleased to share that we have several community partners on tonight's program, the Breast Cancer Alliance, the JCC Association of North America, Jewish Book Council, Jewish Women's Archive, JScreen and the Sharsheret Young Professionals Circle. Tonight's program has been dedicated by the friends and family of Lisa Strobel and Laura Fine in honor of their mother, Adele Selik.

Melissa:

Before we begin, I have a few housekeeping details I'd like to share. This webinar is being recorded and will be posted on Sharsheret's website along with the transcript, but please note that participants' faces and names will not be in the recording. Also, you may have noticed you were muted upon entry, please keep yourself muted throughout the presentation. We actually received some really amazing questions from all of you, during registration and we expect there will be additional questions now, please use the chat box, which you can access from the bottom of your screen and we will do our best to address all questions.

Melissa:

For those of you who are new to Sharsheret, and as a reminder to others, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for more than 20 years. And although we could never have imagined the world that we live in now, through our services, we have been preparing for this moment and continue to be there for each of you, every day. As an introduction to Sharsheret's important work, I want to share a very brief video with you.

Miriam Sabo:

I had woken up and was getting dressed and all of a sudden felt something and I went, "Oh, that doesn't seem right."

Elizabeth Marks:

When I first heard this is cancer, there's that horrible pit in my stomach and overwhelming sadness.

Hazel Donnelly:

I happened to take a at home genetic test and found out from the genetic test that I've had a lot of Ashkenazi Jewish DNA. I was several months later diagnosed with breast cancer. The side effects emotionally for me personally, were far worse than the physical side effects.

Elizabeth Marks:

I could not imagine my life after the surgery. I didn't know what that was going to look like, I couldn't visualize it. So I had it in my head that maybe I wasn't going to survive the surgery.

Miriam Sabo:

It was a no-brainer that I was going to reach out to Sharsheret. I was eventually placed with Rachel, who is phenomenal. It's just having a friend who understands, who I don't have to explain the lingo.

Elizabeth Marks:

What Sharsheret did for me, and what the social worker did, she provided what's called a link. It's a peer support. We were on the phone for about two and a half hours. It was like soul sisters from the very beginning. And it enabled me to be more positive going into the surgery. That's Sharsheret. That's what Sharsheret does. Sharsheret is that hug and Sharsheret is love.

Hazel Donnelly:

My social worker and I speak at least once a month. I call her to tell her all the great things that are happening. I call her when I'm afraid when there's an upcoming test. Every time I get off the telephone, I feel better. I feel empowered.

Elizabeth Marks:

Sharsheret saved my life. Sharsheret gave me hope.

Miriam Sabo:

It just gives you this very concrete, but very safe place to go to.

Elizabeth Marks:

I knew that I was going to survive the surgery and I was going to be running again. And now I'm running for team Sharsheret.

Melissa:

Thank you. Okay. As we move into the webinar itself, I just want to remind you that Sharsheret is a national not-for-profit, cancer support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret and on tonight's webinar is not a substitute for medical advice or treatment for a specific medical condition. Always seek the advice of your physician or a qualified health care provider with any questions you may have.

Melissa:

Tonight, we have an amazing treat. Three amazing inspirational women. The author of tonight's book *Beat Breast Cancer Like a Boss*, Ali Rogin, is with us and she is joined by two women featured in her book. Joan Lunden helped wake up millions of Americans for two decades as host of *Good Morning America*. She's an Emmy Award winning journalist and *New York Times* best-selling author and a leading health and wellness advocate. In 2014, Joan found herself facing a breast cancer diagnosis, which she immediately turned into a mission to educate and inspire others about prevention, treatment and survival. She did this by chronicling her experience in her book, *Had I Known*, and advocating for other survivors on Capitol Hill. She is the host of *Second Opinion with Joan Lunden*, premiering on PBS stations everywhere on January 30th, in just a couple of weeks, and her latest book, *Why Did I Come into This Room? A Candid Conversation about Aging*, quickly became a *New York Times* bestseller.

Melissa:

Jill Kargman is a *New York Times* bestselling author of 12 books including her most recent, *Sprinkle Glitter on My Grave*, and the creator and star of *Odd Mom Out* streaming on Peacock. After learning she carries a CHEK2 mutation, she opted for a prophylactic mastectomy. Her experience with melanoma and learning of the mutation dramatically increased her risk for breast cancer, taught her the importance of advocating for yourself in medical settings.

Melissa:

And of course, Ali Rogin is a producer with the *PBS News Hour* foreign affairs team, writing and reporting pieces for TV and the web. Her reports have also been featured on MSNBC, ABC, Sirius XM and nationally syndicated FM radio shows. She is a 10-year veteran of DC's political scene covering White House, Capitol Hill and the State Department. Although that's not what she'll be speaking about tonight. She covered the 2012 election first as a campaign embed during the Republican primary and then as part of Obama's reelection campaign press corps during the general election.

Melissa:

During her senior year at NYU, she discovered she had a BRCA genetic mutation and decided to have prophylactic surgery before her graduation. *Beat Breast Cancer Like a Boss* is her first book. So Ali, first of all, I am so grateful that you are here with us tonight and you brought two amazing friends that you made while writing the book. I'd like to start by asking you a couple of questions, then I will leave it to you to speak with Joan and Jill and then we'll get to participant questions.

Melissa:

Interestingly, both of the questions I have, have to do with timing. So you learned that you carry a BRCA mutation while you were in college. Not only that, but you learned you inherited it from your father. That actually brings up a lot of interesting points that people don't often realize, including that men can carry these mutations and pass those mutations down to male or female children. I guess when we hear breast cancer, we think women, but BRCA mutations impact risk not only for breast or ovarian cancers, but male breast cancer, melanoma, pancreatic and prostate cancers too. And while we're talking about information that people are unaware of tonight, we'll also learn that it's not just BRCA mutations that impact risk, but mutations like CHEK2, ATM, PALB2 and others.

Melissa:

But you're in college, most people are worried about upcoming exams, the next party they're going to go to and you've had to digest some very difficult news. First, how did you do that at such a young age? And why did you decide to take action during a spring break, your senior year, as I understand. That's earlier than many would choose to.

Ali Rogin:

Yeah, Melissa, thank you so much. And thank you to Joan and Jill for being a part of this, and obviously for speaking in my book. Their stories are absolutely incredible. But yeah, I tested positive for the BRCA1 mutation. Actually, I think it was when I was a junior in college. And my parents, my dad had actually learned many years prior, that he was BRCA positive and he knew to get tested because his sister, my aunt had ovarian cancer at a very young age and she sadly passed away of it.

Ali Rogin:

So they waited to tell me until they thought I could handle the news and make a decision that was right for me. And so I immediately went to the NYU Medical Center and met with a genetic counselor, got the results back a couple of weeks later. And I did not act right away. I actually took a little time to sit on the news, actually. I went and studied abroad the first semester of my senior year and then I came back and faced reality and met with a surgical oncologist who told me that more and more young women were getting prophylactic mastectomies, and I thought, "This is a no-brainer, I want to remove the ticking

time bomb on my chest, I want to get going with the rest of my life. And I don't want to worry about this every time I feel something in the shower." And that's really what motivated me to take action so early.

Ali Rogin:

I also thought about it from the perspective of not having to worry about taking time off from work, if I were to wait until after I graduated. I was very lucky that I was able to... I did it over spring break, as you said, and I was able to come recuperate at home. And I joke, it's a very dark joke, but I say that, while some of my peers were in Cabo, showing off their breasts, I was getting mine removed. But it was the best decision I ever made. I'm happy I did it so young. And I am definitely, I think 10, 11 years removed, a testament to the power of prophylactic action, and of course, the idea that knowledge is power.

Melissa:

Absolutely. And you mentioned now you're 10, 11 years removed. And that's actually my second question. This was clearly a life-altering experience. Yet it did happen a while ago that you learned this and took action. And while many people would be happy to put the experience behind them, perhaps close that door, you chose to dive back in, a decade later, and write a book about it. And write a book about the whole, not just your experience, but sharing other people. So why did you choose to go back to that time and experience? And has it had an impact on you now?

Ali Rogin:

Yeah. I'm a storyteller by trade. I'm a journalist, I've worked in TV news my whole career and the best advice that we as journalists, as writers get, is write what you know. And this was certainly something that I knew firsthand, and felt very passionate about, realized a few years ago that there wasn't really a resource out there that provided a collection of stories from people, women who are out there, who have achieved other great things in their careers and in their lives, who might also have wisdom to pass down to readers about their experience with breast cancer.

Ali Rogin:

And so that's really what motivated me to write the book. And I think it's something certainly that Joan and Jill also share with me, this idea that in telling our own stories, we help other people, but we also help ourselves. And writing down my story, certainly allowed me to reflect on it, steel myself for the challenges ahead, when it comes to reducing my risk for ovarian cancer, which still I'm looking ahead at. And so that's really why I chose to tell this story, and it's something that I continue to be really passionate about.

Melissa:

That's clear. Thank you so much for sharing. I'm actually going to take a step back now and invite Joan and Jill up to the front of the screen to share some of their experiences and answer some questions that Ali is going to present.

Ali Rogin:

Joan, Jill, thank you so much. And to pick up where Melissa and I left off, I think all of us believe that there's so much power in sharing our stories and you both have done so in incredibly powerful ways. Obviously Joan, from the moment you disclosed on Good Morning America that you were one in eight women to hear the words, you have breast cancer. Jill, you wrote about your experience with the CHEK2

mutation in an incredibly powerful essay in *Tablet Magazine* talking about how the pain from your surgery was nothing compared to the emotional pain that you were experiencing while your son was dealing with antisemitism at school.

Ali Rogin:

So for both of you, I want to know, what did sharing your story do for you, and of course, what did it teach you about, I suppose the power of sharing our stories with others? Joan, why don't we start with you?

Joan Lunden:

Well, I really truly am a believer that every time we share our story, no matter what it is, no matter how we're being tested, that we have the opportunity to help others. Not only to disseminate the information that we've learned along our journey, but also just to relate and connect and let that person not feel alone, and let that person not feel like only they are going through it. And they think, "Oh, my gosh, I spent my mornings with Joan and here, she's going through it too."

Joan Lunden:

And personally, I was a doctor's daughter, or my dad was a cancer surgeon, I always thought I would grow up to be a doctor, always. And then I worked in a hospital the summer before college, I figured out right away that shots and scalpels, they just weren't going to be in my career. But I always was passionate about disseminating health information. Because there are many ways you can help others stay healthy. But to be very honest, within about 24 hours, 48 hours after my initially hearing, you have cancer, it dawned on me that I had just had this amazing opportunity dropped in my lap to follow my dad's legacy, to take the baton and run.

Joan Lunden:

And so I took a camera in with me to every single appointment that I went on, and I started sharing it. And I've heard from so many people, thank you for sharing all of those because you took the scary out of it. Because they could see what it looked like, in radiation, they could see what it looked like. Like when I went in to get the port put in, all of those things. And so instead of being some big mystery that could just stress them out, they saw what it was like.

Joan Lunden:

And probably one of the hardest things I ever had to decide to do was to do the cover of *People* magazine bald. They came to me, they wanted me to do it. I don't even know if when the photographer walked into my home that morning, whether I truly realized or had made a decision yet as to whether I was really going to do it bald. Because when you lose your hair, I mean everybody out there, every woman knows, it's just the weirdest thing in the world. And not to be vain, but your hair does a lot for your looks. And I didn't run around all the time myself bald, I usually wore a wig or a little hat. And we photographed me with my wig, we photographed me with then a scarf, and then we cleared the room and he said, "All right, let's take the scarf off." And it was really intimidating. They're so close, right up for you. And I said to myself, "If you have ever dug down inside yourself and your soul and your heart to put a smile on your face, it's now because that's pretty much all it's going to be."

Joan Lunden:

And I had a woman not too long ago tell me, she wrote me, it's not somebody I knew. But she wrote me on Facebook and said, "I just got diagnosed with cancer, breast cancer. And I must say to you that the first thing I thought of, when I heard those words, was your face on *People* magazine." She said, "Not really your face, your smile. That smile told me you did it and I can do it too. And it gave me so much strength and hope." And that just makes all of this worthwhile. So I think it's helped me personally and it's helped, I hope, many, many others.

Ali Rogin:

Without a doubt. Jill, let's hear a little bit from you about how sharing your story, which I think Sharsheret, especially the people listening tonight will find it really resonates with them. How did that help you and what have you learned since?

Jill Kargman:

Well, first I want to say that Joan, you are so brave, and I remember that cover and it's because of women like you that gave my generation X genetic group the ability to do this. And you did pass the baton to us. And I can't thank you enough for that. And I do feel like that was a breakthrough image and there is something just amazing about your smile and just your strength as a woman. So thank you.

Jill Kargman:

My story is different from everybody in the video pretty much, only because I didn't have to hear those words. I had a lump and I didn't even feel it in the shower or anything, and I did the breast exams and all that because my mother has so much breast cancer on her side. Her little sister got it at 36, her mom died at 46. So I always had this emotional sword of Damocles over my shoulder. And whenever people talked about breast cancer or mammograms, I felt like I was a time bomb even before I had any information. And ironically, Ali, I have the exact same situation as you which I only found out subsequent to our phone conversations, in that the gene that I inherited came from my dad, not my mom's side.

Jill Kargman:

I basically had a lump that the mammogram picked up, I started my mammograms at 35, because of my mother's side breast cancer history. And so they had that baseline, younger than most. And then, I guess I was 42, they said, "You have something that we need to do, a needle biopsy." So I did that and then they said, "Sure enough, it is a pre-cancer cell and it eventually will mutate, keep burgeoning and it would be good to get a BRCA panel done with a genetic counselor." And I said, "Funny you should say that because I did it six months ago at Sloan Kettering, but I still hadn't heard the results, it takes a long time."

Jill Kargman:

And two weeks later, while I was waiting to do my lumpectomy, they said it would just be in and out lumpectomy, sleep in your own bed that night. I got this result that I had a CHEK mutation. And at this point, my parents hadn't been genetically tested. So I didn't know who had passed it on. But the second I had that information, I knew that I wanted to just rip the band aid off, so to speak.

Jill Kargman:

And in terms of sharing and your question, I had a friend who I confided all this to, and she told me about this other friend of hers who wanted to be really private, but we were friendly. So she said, "Let me ask if I can tell you who it is." So then she called me and she's what I call my tits fairy, and much like the video that you showed, we talked for two hours and we were very forthcoming about our, I told her what I was worried about, and she completed my sentences and she has a really good sense of humor and we wound up laughing a lot. But she texted me all the things I would need for the double mastectomy, she gave me her surgeon and plastic surgeon for reconstruction.

Jill Kargman:

And I just felt really safe that she had gone through this, I didn't even know it because she didn't want to tell anybody. But she looks great. I saw her all the time. And she had the BRCA2 gene and she just did it sub rosa without anyone knowing and I have a different approach, I feel very much in the same way you did where, you get support. I need support from my friends and my parents and everybody. So I felt totally comfortable telling everyone. But you also touched on, at the moment, well, two days after I got home or two days after my surgery, the day I got home, my son had this little Nazi shit in his class who said, "God sent Hitler to kill the Jews because you nailed Jesus to the cross." So he was really upset and I flipped my shit. I didn't cry at all about the double mastectomy, I had the drains with the pus and the blood and I didn't even care. And then I burst into tears.

Jill Kargman:

So when I called my parents, my dad said, "Well, I know you're emotional about this, but don't forget, you just went through this whole surgery." And like in sitcoms when they accuse the wife of being a bitch because she has her period, I was like, "It's not because of my surgery." It really didn't feel tied to any of it at all. I mean, maybe I was a bit weakened emotionally because I was a little sleep deprived, and that's a possibility. But truly, I wasn't that upset about going through it because I felt lucky that I didn't have to do chemo and radiation. I only framed it in gratitude that my quote, journey was so much easier than most women's. So I really didn't get that upset about it, I was truly more upset about these freaks in my son's class.

Ali Rogin:

Yeah. And the way that you conveyed those emotions, I recommend obviously, that article to anybody who is thinking about doing prophylactic surgery because your story is so powerful and Joan, everything you've... I mean, putting this book together, I watched some of the videos that you had recorded of you going in for your procedure to get your port inserted, and it is raw and real and in real time. And I can't imagine how many people you've helped by documenting that. You're clearly, always thinking like a journalist. So it's really incredible. Melissa, do you want to-

Joan Lunden:

It's funny Ali, though, that I'm the other way around as Jill, because I feel I got off easy, because I didn't have to have a mastectomy. I only had to go through a year of chemo and radiation and no hair, but I didn't have to do a mastectomy, I didn't have to do reconstructive surgery. So I felt that I didn't have it half as bad as everybody else.

Ali Rogin:

I think that's really a testament to how we all, it can be really powerful to orient yourself in a way of thinking positively about things. I mean, Joan, you had triple, was it triple positive, I'm sorry, or triple negative?

Joan Lunden:

I had triple negative. And I'll be honest, when they first told me that, I didn't know anything about breast cancer, I'd never had a friend that went through it or a relative. And she said you're triple negative. And I thought, "Oh, good. At least I'm negative to three things." And then she said, "No, no, no, what that means is that you're not estrogen positive, or progesterone positive, or HER2. Those are the three main kinds of breast cancer. And what this means is that if you don't have any of those receptors on your cells, then you can't use any of the targeted therapy that scientists have come up with. All you can do is take six months of chemo."

Joan Lunden:

And when I heard that, I had gone over there thinking, "Maybe I'll have to have a lumpectomy. I'll go in, have a little surgery, no one will ever know, maybe I'll have to have a little radiation, I can put a hat on, I can put some sunglasses on." Because your first inclination is that you don't want to tell anybody. And I'm like anybody else. And on top of that, I was a public figure. And I was a health advocate. I felt like I was letting people down in a way. And so I at first didn't want to tell a soul about it. And I realized when she said, "You're going to have chemo," I have to admit, the first thing I said was, "So you mean I'm going to lose my hair?" And she said, "Oh, yeah."

Joan Lunden:

And I immediately called Robin Roberts, who had my job from years ago, and who had gone through all this and she immediately said, "Number one, shave your head. Don't let it just start falling out all over everything. You'll see it on your pillowcase. You do it to the cancer, don't let the cancer do it to you." So I walked into a hair salon in Greenwich, Connecticut, where I live, not my normal one because they would have talked me out of it. I walked into one that I didn't know anybody. And I said, "I'd like to have my head shaved." And these women behind the counter looked at me like I was from Mars.

Joan Lunden:

But this hairdresser, a big tall guy, he was standing there and he said, "Follow me. And he took me back into the back, and he picked up the razor, the electric razor, and put my head down and started going this, I said, "Wait a minute, wait a minute. I got to have this on tape." So I got my phone and started videoing it, and it's the weirdest thing because we've never gone through that and you hear this buzzing and it's vibrating and it's right by your ear, you think it's going to cut your ear off. It was the weirdest thing and then I just sat there and looked in the mirror and I mean there's just nothing stranger.

Joan Lunden:

But the day your eyebrows and your eyelashes fall out, I went on the TODAY show, sorry, I work with the TODAY show. When I went on the TODAY show to be on with women's breast cancer day in October, the night before I washed my face. This is about three months into my treatment. And when I took the towel afterwards and wiped my face off, I looked back in the mirror and all my eyebrows were gone and all my eyelashes were gone. And it looked like somebody had just taken an eraser and erased my face. So I called my makeup artist and said, "Boy, are you going to earn your money tomorrow morning."

Ali Rogin:

Oh, my God. That's incredible. And I mean we could talk for hours about this. I do want to, before we open it up to questions, I want to touch on another thing that both Joan and Jill talk about in the book, which is, when you're going through something like this, obviously your doctors play a very important role. And you both, I think have had really powerful experiences in terms of the patient-doctor relationship, that I think it might be beneficial to spend a couple of minutes talking about, Joan, in your case, as you mentioned, you are the daughter of a physician and you grew up in an atmosphere of putting that doctor on a pedestal and you do not question the physician.

Joan Lunden:

Yeah.

Ali Rogin:

And I know that your daughter was the one who had to tell you, "No, mom, we need you to go for a second opinion. You need to talk to somebody else." And that opened up a whole nother Pandora's box for you, and Jill-

Joan Lunden:

It was very unethical for me to do that, to question what a doctor tells you. But I have three older daughters, Jamie, Lindsay and Sarah, all huge fans of Jill's. And they just said, "Uh-uh (negative), Uh-uh (negative). In today's world, there's so much new treatments coming down the pike all the time, you've got to get a second opinion." The problem with getting a second opinion is that sometimes you really get a second opinion. A completely diverse, nothing like the first one. The first one wanted to do the standard of care. Surgery and AC-T. And the other one I went to, wanted to do this brand new, at the time it was really new, called neoadjuvant which means you do your chemo first and the whole idea, and she said, "Because if the chemo really works on you, it could completely take away, completely your cancer and then your surgery will be minuscule."

Joan Lunden:

If I had done it the other way, I would have absolutely had to have had reconstructive surgery. But I went with the chemo first and they also flipped it, I did the T, the Taxol first then the AC, I added something called Carboplatin, which the second doctor said, "No, no, no, no, that's way too strong and serious." I said, "I have a strong and serious cancer. I have triple negative. So I'm going to send in the Army, the Navy and Air Force." So I took the new treatment, and by the time we got to the surgery, I'd had a 95%, I didn't have a complete pathologic response, but almost. So my surgery was very, very little. That's why I ended up not having to go through all those reconstructive surgeries.

Ali Rogin:

There you go.

Joan Lunden:

But I'll tell you, I did go back to my doctor, my original doctor the gynecologist and I read him the riot act, because I didn't realize that I had dense breast tissue. And when you go to get a mammogram, you hate it when they come back and they say, "We'd like to have some more pictures." Really. And I would always say, "Why? Did you see something bad?" And they would all say the same thing, "No. It's just

hard to see anything because you have very dense breast tissue." And I was like, "Okay. I didn't know that that was something I should know about." And the fact is, is that I had a 3D mammogram, the day of my diagnosis and I got a clean bill of health.

Joan Lunden:

And I could have walked out of that radiology lab right then and there, and I had triple negative. It's an incredibly fast growing aggressive cancer. If I hadn't done that, I might not be here with you guys today. But thank God I had gone on an interview, I was interviewing Dr. Susan Love, a breast cancer expert. She wrote *The Breast Cancer Book*. And we just were chit chatting, they were setting up lights. And I told her about how this always make... I said, "I find mammograms so stressful because they're always calling me in for more pictures." And when she heard me say very dense breast tissue, she said, "Well, wait a minute, wait a minute. Do you also get ultrasounds?" If I hadn't gone on that interview, that particular interview, I would not have known to get that ultrasound, where 10 minutes after having a clean mammogram, I had an ultrasound and they said, "You have breast cancer."

Joan Lunden:

So I think it's so important for women to understand what dense breast tissue is and every woman, just like they say, "Know your numbers," your resting heart rate and your blood sugar level and all that, you also need to know your breast density. It can be one, two, three or four. And if it's three or definitely if it's four, you need to have an ancillary test. That's really important. And all of us, should do our self-exams. Because that's the only way you know what your normal is. And if you know what your normal is, then I can't tell you how many women tell me, the co-author of my book on breast cancer went and got a clean 3D mammogram, a month later, she felt a lump. And sure enough, she turned out to be BRCA positive and had a double mastectomy and reconstructive surgery. A lot of women find their own breast cancer.

Joan Lunden:

So we all have to put on our big girl pants, and do that test and make sure that we understand. And if you're just lumpy and bumpy, like some women are, that doesn't mean you have dense breast tissue. You can't feel it necessarily, you have to have a mammogram in order to find out. But ask.

Ali Rogin:

Exactly. And it is so critical that we all act as our best advocate when we're meeting with the doctor. And Jill, I think you really embody that experience because you went through a horrible chapter with melanoma before the breast stuff even factored in. And I know that that taught you a lot about empowering yourself, when you're talking to a doctor who's trying to push one thing or another on you. So can you tell us a little bit about that experience?

Jill Kargman:

Yes. And actually, melanoma is part of the CHEK2 umbrella. So it was all connected to the breast stuff. Basically, I had a mole on my upper, upper thigh where the sun don't shine. And I'm very pale, and I never go in the sun. And it just kept bleeding and I was pregnant with my third child. And every time I would get out of the shower, there would be blood on the white towel from this mole and there would be a stream of blood. So I went to the dermatologist, I've moles all over there. I'm covered with hundreds. And he's apparently the best, whatever that means, but reputable little Fifth Avenue office that's always packed and you come in like a factory, 15 minutes slots for hundreds of dollars. And he

does his perfunctory thing with the loop. And he said, "It's benign, it's fine, don't worry about it." And I said, "Okay."

Jill Kargman:

So then I went back six months later for my checkup, and I said, "This mole keeps bleeding." And he goes, "Well, you're pregnant, your gums are bleeding, you're pregnant. It's normal." So I said, "Okay." So then I had the baby and I went back again six months later, and I said, "It's still bleeding." And he said, "You're being hysterical." And that word to me is so sexist because it's the Greek root of hysteria which means uterus, and I just was annoyed and I wondered at the time, "If I were a man, would he have said that to me?"

Jill Kargman:

So after my son was like one or one and a half, I said to him, "I'd like to get Botox right here in my elevens," because I had a furrowed brow. And he said, "I don't inject that. You need to get what I call a scumbag dermatologist. Now dermatology everyone thinks of it as vanity and beauty, but I'm here to save lives." So I said, "All right." So I talked to my friend and she goes, "Go to this cool mom. She's really sweet. She has three kids. She's not a scumbag. She's a super nice down to earth lady." And I went to her, she did my Botox. And then she said, "Is there anything else you want to ask?" And I said, "Actually, I have this mole that keeps bleeding. But this doctor," who she knew, because he's very revered, "he dismissed it as benign." She goes, "Let me just take a look at it." And she goes, "It looks benign to me, but if it's been bleeding for two years, I really would like to take it off." So I said, "Great."

Jill Kargman:

So she took it off. And three days later, she called me I was pushing the stroller, pouring rain and she said, "You have a really bad melanoma. It's the worst kind of melanoma and you need to call Sloan Kettering right now and call Daniel Coit, he's the head of tumors for such things. And they have to ascertain exactly the size of it," because she knew that it was way beyond the circumference of the mole she took off. So they do these radioactive dye injections around my thigh, and said I had stage three melanoma, and that they had to take one pound of flesh out of my thigh.

Jill Kargman:

So I was in a wheelchair, and then I had a cane for six weeks. It was a major odyssey. And it's because of my vanity basically, that I survived. And here was that first doctor being like, "I save lives. I'm not a Botox scumbag dermatologist." Meanwhile, I would have been dead. Because when I met later with the Melanoma Research Alliance founders, they had heard my story and I was only 34. So it was very unusual to have that at that age. And they put me on Good Morning America, funnily enough, for melanoma awareness to scare the hell out of people who are my age that it can happen to them and to do mole checks the way that we advocate for breast checks.

Jill Kargman:

And the doctor that they had me on with, Mitchell Kline said, "You wouldn't have made it 18 months. You would have been dead." He said, it's very virulent, fast spreading, "You would have been dead in a year and a half." And I had three children under five at that time. So it was absolutely terrifying. And I just feel so lucky that I was vain enough to go get the Botox.

Ali Rogin:

Well, and I think not to give any spoilers away, but you can read all about how that informed Jill's later experiences with reconstruction, in *Beat Breast Cancer Like a Boss*, available on Amazon and booksellers near you. But what I love about what you took from that experience was how it really empowered you to speak to the doctor, level with him or her. You are your own best advocate. And so you were uniquely empowered, I think to say no, when you wanted to say no, or to question whatever it was they were recommending. And I think it's something that can be applied to any health situation any of us are going through or any circumstance where we're in a position that we need to question the authority who is allegedly supposed to be infallible. So Melissa, I think we have 15 ish minutes left, should we turn to some audience questions?

Melissa:

I think that would be great. Thank you guys for sharing your stories. I'm watching the chats come in, and people are really moved by what you've shared. So thank you. And we did get quite a number of questions, both on the chat tonight, but also ahead of time during registration. Some are for specific people, some are for anyone. So I'm just going to dive right in so we can get to as many as possible.

Melissa:

So this question actually comes from the Jewish Book Council, which is one of our community partners on this program. And it can be for anyone who feels strongly about it. What if any, books have shaped your own experiences with breast cancer other than your own? And what role do you hope this book, that you were featured in or wrote or edited, or the books you've written or articles you've written, hope to accomplish for the readers?

Ali Rogin:

I'll take that really quickly. And then I would encourage Joan and Jill to weigh in. The number one book that helped me before I wrote my own was a book called *Pretty Is What Changes* by Jessica Queller. And she went through BRCA years prior to me, it was a book that my plastic surgeon actually recommended to me and I recommend it to anybody going through this. Also, *Why I Wore Lipstick to My Mastectomy* by the wonderful GERALYN LUCAS. We love her. That was also a great inspiring book. And of course, everything by Joan and Jill.

Ali Rogin:

And I would say that, in terms of what I hope my book helps people with, look, I know the title of the book is *Beat Breast Cancer Like a Boss*. But I make very clear in the introduction, that I'm not talking about beating as meaning going into remission and remaining cancer free, because that is one of a number of outcomes that can happen. Some people are living and thriving with metastatic breast cancer, as you saw in the video earlier, some women have had multiple recurrences. And so there are tips and tools in the book to deal with the emotional toll of what it means to go into an office every couple of months and feel that sense of scanxiety. And so that is something that I hope is imparted in the very beginning of the book, so that anybody who thinks that I'm talking about getting rid of breast cancer and getting on with your life, that's very rarely how it actually happens.

Melissa:

That's true.

Joan Lunden:

But I'll tell you, though, when you first get diagnosed, it's just so big. It's so overwhelming. Cancer. I mean, back in the day when my dad was a doctor, sometimes if they didn't catch it really super early, they wouldn't even tell the woman. Because why upset her? There's nothing we can do anyway. Because they didn't have chemo, they didn't have radiation. All they had was surgery. But I can say now that I'm here, as a survivor, as a thriver, which I like both of them, that there is hope and light at the end of the tunnel. Here it is. I'm here, I went through a year. It was a year of my life. Yeah, it was a crummy year, you feel... I mean, as a woman, you just feel so strange when you don't have your hair and your eyebrows and everything. But you know what? Like in the spectrum of a lifetime, it was a year of my life. And I don't even think about it now. It's hardly even, I mean, it's not something that I think about all the time.

Joan Lunden:

So I always like to say to people that even though it seems so major and so overwhelming at the time, that it will, in however many months your treatment is going to take, it will then be over. And I do think that there is an inherent desire or need in every woman, when you finish your treatment and you're a survivor. Go to any survivors tent, at any breast cancer walk or run, and you will hear the same things, there is such a desire to just reach out your hand and grab a hold of the next woman who's fighting her battle and to help her along and to pull her along and try to inspire her and give her some hope. I mean, I remember people used to say to me on Facebook, you go into cancer one person and you come out another. And it's kind of true, because you appreciate the little dumb things in life, because you have life. And there is this desire to help others. It's just something that comes along with the journey.

Melissa:

Absolutely. Jill, did you have something you wanted to add or should we move to the next question, your call?

Jill Kargman:

Oh, we can move on. I really didn't read anything about breast cancer-

Melissa:

Interesting.

Jill Kargman:

... because I just watch comedies. I just watched so much TV and broad [inaudible 00:47:04] and stuff like that, because I was escapist about it. And because I didn't have to research treatments, I just felt like I can put my head in the sand and just do the surgery.

Melissa:

Also a way to go. Absolutely.

Joan Lunden:

Absolutely.

Melissa:

Okay. So you know what? Jill, let me ask you this question. This question, although they aren't all from program partners, this question also happens to be from JScreen, another one of our partners. So how did you talk to your family, whether it was siblings, cousins, parents, about your test results? And what was the reaction? Were people interested in getting tested themselves? Had they had their own experiences they hadn't shared with family? And I also, before you answer, I just want to point out, you said it took such a long time to get your screening results back. But right at this point, it's much, much faster. It's only up to six weeks, maybe. So that's something people should know. But back to the question.

Jill Kargman:

What was weird for me is I felt like I was... I have no medical background whatsoever. And I'm not spiritual at all. When people say, "Listen to your body and be your advocate." That's not me. I really, like Joan had a god complex with doctors and just didn't really think about it that much in terms of questioning. And then once I started piecing together that it was from my dad's side, and that might... So my father's a twin. And he and his twin brother both had renal cancer. And my father's twin brother's daughter had stage three breast cancer and a double mastectomy when she was 40.

Jill Kargman:

You don't have to be Inspector Clouseau to realize that there's a genetic connection. So weirdly, they never got their panels done. I don't know if they were interested or not, but that wasn't anything that was shared with me. And so once I slipped it out and said, "Okay, daddy and I have this, you and uncle David probably do too." I told all my cousins and my brother, and two of my cousins are really, they're in their 20s. So it's like an Ali situation. And I don't think that they're going to do anything about it just yet. They haven't been tested even yet, but I think they feel like my daughter's doctor had said, "We don't want to test her yet because she's turning 18. But what is she going to do with that information now?"

Jill Kargman:

So I think it's a little bit about your personality. Do you want to know? And are you going to act on it? An Ali situation. There was a family member that was extremely young, diagnosed with ovarian but we didn't have any history of any diagnoses in the 20s. Only in the mid to late 30s. So I feel like it depends on your family history, but yeah, all my cousins and everyone knows, but they're just not acting on it as yet.

Melissa:

Okay.

Joan Lunden:

Melissa, we need to make sure that we say to everybody, it's so important to ask these questions. I know somebody that's in the family that had breast cancer, and she was able to just go have some radiation, I think maybe a lumpectomy and she never told her children. And I'm now, I'm going to approach her, and because her children are getting a little bit older, and say, "You have to tell them." She didn't want to tell them because she didn't want to scare them. I mean, I was worried about scaring... My twins were, I don't know, six and eight or something like that. And you tell them age appropriately. But now they're going to get married. And their wives need to know that their mother... And there's a lot of women out there who have had breast cancer, who have not told their family. So

you must go back and ask your mom, "Did you ever have breast cancer? Tell me now because I'm a grown up. And I need to know." And-

Melissa:

By the way, it's not just breast cancer.

Joan Lunden:

Right.

Melissa:

We know that some of the mutations affect cancers that wouldn't seem necessarily related, but clearly are. Sharsheret's actually-

Joan Lunden:

You've got to go up dad's side, too.

Melissa:

Yes, absolutely. Sharsheret has a booklet called talking to your children about your breast cancer gene. And we also have a genetic counselor on staff. So for people who are interested in learning whether they should be getting one and what the right screening would be for them, or are thinking about it and just really need to talk it through or thinking about talking to their children, we have a lot of great resources, free resources that are available.

Melissa:

All right, I'm cognizant of the time, so let's move on. Joan, you actually alluded to this. So somebody asked, the word survivor has a bit of a controversy surrounding it. Some really embrace it, some choose to be survivors the day of their diagnosis, others choose to be survivors only five years after their last treatment. Others shun that word completely and talk about thrivers. So I wonder what you think of those words and what those words mean to me. And somebody actually asked this evening, how do we act when people ask you if you're now cancer free?

Joan Lunden:

Well, once you tell the world, in my case, that you have cancer, the one thing that happens is that everybody that sees you, that's all they talk about. And you just have to know that going out. And people ask me if I'm cancer-free. And once again, I feel like I'm so much luckier than so many other women who have to take medications, ongoing for decades or the rest of their life. I had triple negative and you don't take any medication after that. And because it is so aggressive and so fast growing, pretty much after three years, if it hasn't come back, and after five years, and I'm now six years NED. I saw somebody who just said-

Melissa:

Yes.

Joan Lunden:

... funny you just said in 12 and a half years NED. That's something I learned from all my BFFs on Facebook that I don't really know, but gosh, I learned so much from them. And they taught me a lot. And being NED after five years with my kind of cancer means you are cancer-free. Because it would have to have grown back. After battling for a year, I was happy to be a survivor. Because I had fought hard. I mean, I almost took on my cancer like a job and learning everything I could about what I needed to be doing, what I needed to be eating during that year so I wouldn't have all the problems that people go through on chemo. But now that I've passed that, and it's in my rear view mirror, I love the moniker thriver. I think we all want to be thrivers especially as we age as women.

Melissa:

That's a great way of putting that. Okay. So being cognizant of the time, we'll just ask a couple of more questions. So we received several questions about moving beyond the experience or struggling to get back to the person they were despite changes to the body and ongoing pain and things like that. And although I want a lot of input to this, but in the book, Joan, you're specifically quoted as saying you go into cancer one person and you come out another. So are you even trying, the three of you, to get back to who you were and how do you move beyond the trauma, the cancer experience, the ongoing pain, things like that? Ali, can we start with you? I mean, I know you didn't have cancer, but you had something you had to deal with that was within the cancer world.

Ali Rogin:

Sure. I mean, it's something that I look at myself and I see these battle scars, and I'm very proud of them. It's shaped who I am, and how I approach challenges in my life. But also, I feel so lucky that I was able to look into my genetic future and take action. So again, yeah, I didn't have all the negative, maybe baggage is the wrong word. Because it's not baggage if you're going through this, but I didn't have that hanging over my head. This was ultimately an incredibly positive experience overall.

Melissa:

Amazing. Jill? Oh, you're muted Jill.

Jill Kargman:

Sorry. I was at a doctor who said... He saw my scar from my melanomas, about a foot long. And he said, "You know you could laser that." And I said, "Nope. I don't need to. Never would think to do that." I have a lot of tattoos from different periods in my life and I wanted to get one now that says, nous sommes nos cicatrices, we are our scars. And to me, I wear it with pride. I would never laser them and with my breast scars they're under the boob, those smiles. So they're really not visible. I mean, it's still an adjustment having implants. It's funny because I feel so bitchy, but for so many years, I would make fun of women with implants because I just thought it was like they had that big Los Angeles balloon boobs. And now, I don't have that size, but I just look in a bathing suit, I feel like I'm being bimbo, but it wasn't by choice in terms of that.

Jill Kargman:

So yeah, that's weird. It's weird. I liked my low boobs. It felt like European. I didn't care that they were low riders. Yeah. I wouldn't go backwards, I'm so much happier and I definitely love that I don't have to stress about mammograms. By the way, one thing I do want to say for anyone who has family members who've been blowing up their mammograms due to the pandemic, please pressure them. Because I had

to force my best friend to go because she was scared to get it done during this time. And it's more important than ever.

Melissa:

You're 100% right there. In some parts of the country, routine screenings are down 90%. And the National Cancer Institute, NCI, has issued a statement that they expect the pandemic to negatively impact cancer deaths for the next decade. So these places know now how to keep you safe during it. It is not an excuse anymore to not go. That's important to keep in mind.

Melissa:

Okay, why don't we finish with a question from the Breast Cancer Alliance. So I think this is a great place to finish, because it's a great parting message. So if you could name one thing, and I'm going to ask each of you, one thing that got you through. A mantra, a particular form of exercise, a message you kept repeating, an activity, a person, what was it that was most helpful to you? Joan, why don't we start with you because you were the... Let's start with you.

Joan Lunden:

Well, I think that I focused on what would make me survive the best and what would get me through it. What foods I should eat, the fact that I tried to do something even. Every day, I was not feeling well enough to really go work out but I would even stretch, I did something. I mean, I really took it on and said, like you say in the book Ali, I beat my cancer like a boss. And I became the boss of my cancer treatment. And I remember the last day of my treatment, I said to my oncologist, "Are we just supposed to walk out of here and assume that we got it? Because I'm hearing from everybody, on Facebook, do you have the fear of getting it again?" And he said, "Oh, you're going to follow the wise words of the great philosopher, Wile E. Coyote." I said, "What?" He said, "You know that cartoon character that would run off the edge of a cliff at like 100 miles an hour? Well, he was never in trouble, until he looked down. You just keep your head up. You expect to live a long, healthy life. You did everything that you could to beat this and just don't look down." And that's how I'm living my life.

Melissa:

That's great. That's a great way to be living your life. Ali.

Ali Rogin:

I highly recommend anybody going through this, number one I think this is something, Jill, that your tits fairy also recommended was the marsupial pouches. I actually did not have those from my reconstructive surgery. But I have since suggested to other of my friends who've done this, to get them. It allows for the drains to not hang off your body, which to me that was the most discomfort. Because I had the Toradol to deal with the incredible after effects of the surgery, but it was the drains that irritated me for weeks after.

Ali Rogin:

One other thing is, it's hard to shower in the weeks after you have a mastectomy. So I don't know, like a week in or something, I went to the hair salon and got a blowout. And it made me feel like a new person because you feel gross. And so I think there's a whole philosophy about looking good, feeling good. And

that is something that I think is very important to keep in mind whenever we're going through anything like this.

Melissa:

Oh that's great. That's great advice. Jill.

Jill Kargman:

That's so true. I went to Drybar all the time. This is really after my double mastectomy. But the melanoma surgery, I had a social worker at Sloan Kettering who said, "Don't ever forget that stress," because they have a list of cancer causing foods and carcinogenic sodas and all these things you're supposed to cut out. But she said, "Cortisol, the stress hormone is the worst of all." And so I feel like I turned a corner, and per Joan's amazing image of coming out the other side. I don't sweat the small stuff as much. I used to get nervous about stupid shit and I just don't anymore. I never sweat the small stuff. Because if I feel my cortisol rising, I just need to exhale and take a step back. Because I know that feeling. It's like when you're going down the stairs and you skip a step and you feel that jolt, that's bad for you. So I just try to relax and light candles, and I'm not a meditation person, but I'll read a book or anything to calm because stress is really bad.

Melissa:

Yeah, absolutely. It's actually incredibly gratifying to me to hear the things that you've all talked about and to know that Sharsheret very often has something that can help support. Like Ali, you were talking about that blowout and how it made such a big difference. And we have what we call our Best Face Forward kit, our BFF, which provides all sorts of paraben-free lotions and makeups and brow guides. And all sorts of resources like that. Jill, you mentioned your social worker, we have social workers who you can talk to help reduce your stress and learn some coping mechanisms. And just to be that friend that's there for you, who can help you through this cancer experience, whatever your cancer experience is.

Melissa:

Listen, I could continue this conversation for another hour, easy, but I want to be fair with everybody's time. So I want to thank all of you for sharing so much of yourselves tonight. You've made what is a difficult topic more accessible and more hopeful. And that has made for a wonderful evening.

Melissa:

So right now, I have a couple of more things I want to share very quickly. But right now there's a quick evaluation survey, a link to one, that's being placed in the chat box. You can click it now and still listen to what I'm saying. But it would be very helpful to us if you could take a moment to fill out these evaluations because they really do inform future programming. And I am happy to share that from all of the surveys that come in tonight, one person is going to win a personalized autographed copy of tonight's book, *Beat Breast Cancer Like a Boss*, thank you, Ali. So that link is in there now.

Melissa:

I want to again, thank the friends and family of Lisa Strobel and Laura Fine who sponsored this evening in honor of their mother, Adele Selik, of blessed memory. Again, thank you to the Bassett Center for BRCA for their dedication to genetic awareness and education. And again, I want to thank our

community partners, Breast Cancer Alliance, JCC Association of North America, Jewish Book Council, Jewish Women's Archive, JScreen and Sharsheret's Young Professionals Circle.

Melissa:

As we close, I want to remind you that Sharsheret's team is there for you and your loved ones during this time. We provide free support and programs designed to help you navigate the cancer experience. Again, all free, all completely private and one-on-one. Contact information is across your screen right now. And two things I want to make you aware of, first of all, we actually have another book club scheduled and Ali made it very easy to promote this one because Jessica Queller, the author you mentioned *Pretty Is What Changes*, will be joining us on Sunday, March 7th. You'll get information about that.

Melissa:

And this coming Tuesday, we happen to have at, 1:00 Eastern, 10 Pacific, a webinar on cancer brain fog, sometimes known as chemo brain, but that's a misnomer because there are a lot of reasons it can happen. So registration can be found on our website or in the chat box. Again, thank you, Ali, Joan, Jill. So grateful that you joined us this evening. So grateful that so many people came on to hear your stories and learn more. And again, take a moment to fill out that evaluation and win a copy of *Beat Breast Cancer Like a Boss*. All right. Good night, everyone. Thank you for joining us.

Jill Kargman:

Thank you.

Ali Rogin:

Okay. Thank you so much.

Melissa:

Thank you.