

Sharsheret's National Book Club

with Jessica Queller

National Webinar Transcript

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Presented by:



SHARSHERET[®]
The Jewish Breast & Ovarian Cancer Community

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Jenna:

Welcome everybody. Thank you so much for attending tonight's book club event. This is our third book club in our Sharsheret series. I'm our California Regional Director for Sharsheret, and I am so pleased and honored to be interviewing Jessica Queller tonight, the author of *Pretty is What Changes*. I want to thank several of our community partners for tonight's program. JScreen, the Minkoff Center for Jewish Genetics, the Norton & Elaine Sarnoff Center for Jewish Genetics, Temple Israel of Hollywood, and the Victor Center for the Prevention of Jewish Genetic Diseases.

Jenna:

A special thank you to the Basser Center for BRCA for their support and their dedication to genetics education. Before we get started, just a few housekeeping things. This webinar is being recorded and will be posted on Sharsheret's website along with a transcript, but your faces will not be in the recording. If you have to jump off early, you'll be able to catch the rest of this later. If you want to share with any friends or family, please do so.

Jenna:

You may have noticed that all participants have been muted when you entered the program. You will be kept muted throughout the call. There is going to be a Q&A at the end of the interview, but we're going to ask that you put your questions into the chat box, and then I'll ask those questions, as many as we can get to before the end of the program. For those of you who are new to Sharsheret, we are a national non-profit organization celebrating our 20th year this year.

Jenna:

We provide free psychosocial support to women and their family members facing breast cancer, ovarian cancer, and those who are facing increased genetic risk, the topic that we'll be talking about tonight. We know this is a really difficult time right now, so if you yourself are facing one of those cancers, maybe you're facing a BRCA diagnosis or other genetic mutations, please don't hesitate to reach out to us, or if you're a friend and family member, we're here for you, as well.

Jenna:

One of our programs that you might be interested in learning more about tonight that I wanted to highlight is our Genetics for Life program. It's a program where you can speak one-on-one with our genetic counselor and talk a little bit about your family history, any concerns you have about your cancer risk, and the implications of genetic counseling and testing for you and your family.

Jenna:

I know that we're going to be talking about that subject tonight, so after this program, please know that we have a genetic counselor who's available who offers free support. All of our services are free. I should say that. It's offered by phone, so no matter where you are in the country, our genetic counselor is available to speak to you. Just a medical disclaimer. As we move into the webinar, I want to remind you that Sharsheret is a national non-profit, and we do not provide any medical advice or perform any medical procedures.

Jenna:

The information tonight is not a substitute for medical advice or treatment for specific medical concerns that you have. Always take the advice of your physician or qualified healthcare provider with any questions you have regarding a medical condition. Now it's my pleasure to introduce Jessica Queller, the author of *Pretty is What Changes*. She was born in Manhattan and received her BA in English literature from Tufts University.

Jenna:

Her illustrious career includes producing and writing many hit TV shows of which I am a personal fan of every single one of them. *Felicity, Ed, One Tree Hill, Gilmore Girls, Gossip Girl, the Carrie Diaries, Vegas, and Blood and Oil*. She's currently the executive producer and showrunner of the CW's *Supergirl*. She is part...

Jessica Queller:

Oh, no. Jenna, Jenna. Jenna, you're muted.

Jenna:

Can you hear me now.

Jessica Queller:

Yep.

Jenna:

Jessica is a member of Temple Israel of Hollywood. I don't know if you heard me say that, but I'll say it again. She's a member of our LA Jewish community, and she is a passionate women's health advocate. Before Angelina Jolie, she was the first person to write a *New York Times* op-ed about what it meant to have a BRCA gene mutation. She's a real trailblazer, and I am so thrilled to have you here tonight, Jessica, so thank you for speaking to our Sharsheret community.

Jessica Queller:

I'm so glad to be here tonight.

Jenna:

Hopefully I won't accidentally go on mute again as we're talking. Jessica, I've got so many questions for you, and for all of us who have read the book or those of us who haven't, we just feel so moved by your story and what you mean really for the BRCA community. For you to be one of the first people to speak publicly about your diagnosis, and the implications of what it means. For those of you on this webinar who haven't read the book, can you just talk a little bit about how you came to getting tested and what that journey was like for you?

Jessica Queller:

Of course. Sitting here, all I can think about is my mother sitting here right now. My mother passed away at age 60. Everything I do is for her. The reason I'm here is because of her. I just keep going through my mind right now that before she died, she said, "If I get better, I want to help people. I want to go out and help people, and if I don't, will you do it for me?" I just wanted to honor my mom, Stephanie Queller, for just a quick moment.

Jessica Queller:

This all happened when I was 31 years old. My mother was diagnosed with terminal ovarian cancer. Stage 3C ovarian cancer. They said she had five years to live. In fact, she lived less than two. Prior to that, my mother had had breast cancer at age 52, which she beat. The ovarian cancer was a separate primary cancer. My best friend from high school, Jillian Segal, when my mom was diagnosed with ovarian cancer, Jillian had been on the board of a different organization, the Lynn Cohen Foundation.

Jessica Queller:

She had heard of this cutting-edge test, and she said, "I think because your mom had both breast and ovarian cancer, you are eligible for it. The BRCA test mutation." This is the year 2001. I was 31 when Jillian mentioned it to me, and I was not thinking about my own health. I was thinking about my sick mom, and I said, "Well, that's interesting, but I'm fine." However, it stuck and it was in the back of my mind.

Jessica Queller:

My mother died at the age of 60 when I was 33. It was the most horrific thing I hope I will ever experience in my life, that process, the whole... We'll talk about I more later. At age 34, a year after my mother's death, I started getting my life back together, and I moved back to Los Angeles. My family lives in New York, and I got a TV writing job, which is my career, I thought, "Okay, I'm 34 years old. I lost my mom. I spent the last three years dealing with illness and death and grief. Now I can go to dinner parties."

Jessica Queller:

"I need to fall in love. I want to have a family." On that checklist, I had neglected getting my teeth cleaned, renewing my driver's license, all the things you neglect when you're dealing with an ill family member. On that list was, "You know, I should get that genetic test just for peace of mind. I'm sure I won't have it. There's no cancer in my family except my mom, but I just want to check it off the list that I don't have it."

Jessica Queller:

I cut all the corners. I didn't go for genetic counseling. I had a cousin doctor of my call in the test at a lab, and I found out in a very unproductive, haphazard way that I tested positive on the phone with a stranger lab guy who ran a blood lab. He was barking orders at me. "Who are you? Why did you take this test?" He said, "You tested positive." I actually said, "Positive is a bad thing, right?" Because for a minute, positive sounded like a good thing.

Jessica Queller:

He said, "Yes, it's very bad. You will mostly likely get cancer in your life, and you've got to find someone to help you. Goodbye." Then they sent me the results from Myriad Genetics in the mail which said my statistics, which was I think at the time 87% chance of breast cancer, most likely before the age of 50, and that's how the whole thing started.

Jenna:

Wow, Jessica. You talked about your mother, and dedicated even this conversation to her and her memory. You go into a lot of detail in the book about what it was like to care for your mother. At

Sharsheret, we spend a lot of time supporting caregivers. Is there any advice you can give to people on this call who are caring for a loved one facing cancer right now?

Jessica Queller:

It's funny. I just last night started reading this beautiful book called *Wintering*. I'm selling someone else's book right now. Katherine May. I'm only about 35 pages in, but there was an expression she used that reminded me of when my mother was ill and dying. She said, "There are gaps in the mesh of the everyday world, and sometimes they open up and you fall through them into someplace else while everybody else is living their normal life." That's certainly how I felt when my mom got her diagnosis.

Jessica Queller:

Suddenly the world, like I'd walked through the looking glass and everything was different. My sister and I were living in hospitals. We never left my mother's side. We slept in a cot with her in the hospital bed. She was very frightened. We never left her alone at NYU Hospital forever for a night. She moved into the hospital, one of us moved into the hospital. Then I remember going outside and seeing my high school friend who would say, trying to be normal, and they're like, "Oh, my child didn't get into the kindergarten teacher class I wanted."

Jessica Queller:

I just felt like I'm living in a different universe from all these people I don't relate to what they're saying. I don't understand. I think for me, the most traumatic thing that ever happened to me was my mother's illness and death, and BRCA... People often say, "Was your life split in half when you tested positive for the BRCA mutation?" My answer is my life split in half when my mother got ill. The BRCA was just a contribution of it.

Jessica Queller:

I think there is nothing harder than caring for a loved one, especially if the diagnosis is terminal or close to that, especially if you are a young person, or the person you're caring for is at an age that is not... It's an unfair age to be dealing with those things. As much support as you can surround yourself with with people, it's a club no one wants to be a member of. If you can reach out to people who have lived through this so you don't feel crazy, and you don't feel alone, and you don't have to grin and nod and pretend you care about your friend's kid's kindergarten teacher.

Jessica Queller:

It's a time like no other, and I do think that for me, a lot of soul searching and what matters. It's one of those things that illness and death... It's like all of a sudden, all the superficial stuff falls away, and you can really examine what matters to me? What do I want to devote my energy to? It gives you this fresh lease on life in a sad way. For me, it made me realize no matter what, I wanted to be a mother, and I wanted a child. That was the thing... That was the positive, beautiful thing that came out of the traumatic experience of losing my mother, but support and kindness towards yourself. All I offer.

Jenna:

Yeah. In the book, so much of your journey and what you share with us so beautifully is that decision-making process of what do you do about the BRCA mutation? I have it. I've been presented with some options. What decisions do I make based off the experience I've had with my mom? Can you talk a little

bit about how you weighed those options and ultimately decided on the path you did, knowing what you experienced through your mom?

Jessica Queller:

It makes a lot of sense to me that we're talking a lot about my mom now, because I remember when... First of all, my being public about this subject, it's had a life of its own, and it snowballed. My best friend from college tricked me into not playing ostrich and sticking my head in the sand about my diagnosis. She was an assistant editor at the op-ed page for the *New York Times*, and she wanted me to get the mastectomy right away, and I said, "Back off. I have to have kids. Leave me alone."

Jessica Queller:

Then she said, "How would you like to write an op-ed piece for the *New York Times* about it?" My writer ambition was like, "Me? Write an op-ed piece? In that case I'll become an expert about it." Now I've lost the thread of what I was getting to. My mother. So, I wrote the op-ed piece, which got a lot of attention because this was a subject that was not yet known. It was new. Then I was approached to see if I would be interested in writing a book, and my answer was, "To me, this is all about my mother. There is no way I can write a book about the subject without devoting nearly half of the story to what I witnessed with my mom."

Jessica Queller:

Had I not witnessed the horror of her illness and death, there's no way I could have understood what cancer meant, and there's no way I would have chosen, or certainly not been a leader in choosing prophylactic surgery. When I tell the story, I always spend a lot of time narrating what my young, beautiful mother, what happened to her. I myself am now 52 years old. Sorry, I'm 51. Why am I aging myself? I'm 51. I'll be 52 in November. My mom was told she had five years to live at age 58.

Jessica Queller:

That's not very far from me, and she only lived two, and they were horrific years. My sister and I are our mom's primary caregiver for the last three months of her life. We put on rubber gloves, and we put suppositories in for her. We changed her patches. My mom was, we'll get into this later, but was a fashion designer, and very glamorous, and very beautiful, and very proud. The whole concept of how we were nursing our mom was just unfathomable.

Jessica Queller:

I knew after going through that experience I do not want chemotherapy, I do not want cancer. I don't want this. I don't want this. If there is anything I can do to prevent this happening to me, I will do it. That was the whole motor behind my taking action.

Jenna:

Yeah. You talk a lot about in the book knowledge is power, ignorance is bliss, and how you chose the knowledge is power option, but for your sister, Danielle, she wasn't quite there with you. I was really struck in the book when the *New York Times* op-ed came out that she didn't want to confront to you, but she shared. It thrust her into the spotlight in a way that she didn't want to be, and forced her to look at her decision to not confront it. Can you talk about that dynamic of a sibling not choosing a same path as you in terms of wanting to get tested?

Jenna:

I'm sure people who are on this webinar tonight have faced family dynamics around to test, to not test, people choosing different options, prophylactic surgery versus surveillance. Can you talk a little bit about that dynamic between you and your sister, and how that's evolved over time?

Jessica Queller:

First of all, I'm very lucky that my sister forgave me, because I would not recommend anyone doing what I did, which is outing her story in *the New York Times* without her permission. In retrospect, I don't even know what I was thinking. That was not very sensitive. I was in my own bubble of... That was not very good. She did forgive me, and she is also an advocate now. I'm very blessed that she's a wonderful, wonderful sister.

Jessica Queller:

As I mentioned at the beginning, I didn't choose knowledge exactly on purpose, since I thought I was going to test negative. I didn't give it a lot of deep thought, and I didn't even really know what the information meant, which is also not a very intelligent way to approach this. Once I did find out that I had the mutation, and I started learning about it, it's like you can't close the Pandora's box. Then I felt, "I am going to have this hanging over my head."

Jessica Queller:

I had naturally dense breast tissue, and so every time, the scare of every three months. Is this something? I was pinching myself black and blue trying to feel for lumps. I just felt like... I guess this isn't really an answer to, is knowledge power? It took me a year. It took me a year of obsessing and soul-searching day and night, and day and night, and day and night to make the decision. Again, this was 15, 16 years ago.

Jessica Queller:

This was a time when this was not known very well. Doctors did not know how to advise patients. The doctors would say, "This is a case of science outpacing our ability to know what to do with the data. We don't know." The doctors said, "Good luck. This is your information. It's up to you. You have to make your own decisions." After I did my soul-searching obsessively day and night for a year, I really came away with the fact that if I can... Maybe this is a gift for my mom.

Jessica Queller:

My mother's death is not in vain. My mother's horrific experience could save me and my sister from having to have this meet the same fate. Ultimately, what a gift. What a gift that this is something that I could prevent, and that I had the foresight. That said, the process of going through it was not pleasant. When you're healthy and young and wanting to get on with life, who wants to stop their life for six months or a year and deal with this?

Jessica Queller:

When you weigh the options, I think it was pretty clear, but my sister, it took her longer to come around because it all... She was traumatized from our mother's death. The idea of a mastectomy without cancer was also not only traumatic, it was even the experts, some said it was crazy. It's much different now

than it used to be. She's not someone who was comfortable being a vanguard. Nobody knew if I was wacky or crazy or sane, and only time proved that it was sane, but it wasn't quite clear at the moment.

Jenna:

Yeah, yeah. So many times in the book, people were completely shocked that you were choosing this path. Looking at it 16 years later, it seems it's so common now. It's such an important option that people have, but that's a testament to you that you were able to speak out about it.

Jessica Queller:

The other thing is plastic surgery reconstruction has, even in the 16 years since my surgery, became so much more advanced, and so seamless and beautiful. I think a lot of us had the idea of mastectomy of our grandmothers or aunts, and how terrible that was, and how shameful and hidden and all of that stuff. It's just not at all the case today. Even 16 years ago, it was scarier.

Jenna:

Yeah, yeah. Really another thing that struck me in the book was how many healthcare providers created barriers for you. Whether it was you tracking down the doctor who was going to give you your BRCA results to the plastic surgeon who was trying to convince you to have larger breasts because he thought that's what women wanted, and you were saying no. I think one of the things that we see at Sharsheret a lot is women who are facing healthcare providers that are not listening to their needs, who are making it difficult.

Jenna:

Can you talk a little bit about being a self-advocate, and how you navigate some of these really challenging providers who are not listening to you?

Jessica Queller:

Once again, it goes back to my mom. The two years that I spent with her in and out of NYU Hospital when she was incredibly ill taught me how to be an advocate. I just think of that Shirley MacLaine moment in *Terms of Endearment* when she starts screaming for her daughter, "Give her the drugs." I must have lived that moment about 25 times in the course of those two years. Through the course of... I learned how to navigate the hospital system because my mother is basically living in the hospital, and I started to see just not out of malice, but being overworked and nurses...

Jessica Queller:

You have to anesthetize yourself to survive, and you have crying, wailing patients in every room, and you have to just detach. I learned a lot of lessons on how to advocate for my mother. I am a New Yorker, born and raised pushy New Yorker with a trial lawyer father. I went from being this demure, sweet girl to like, "Uh-uh (negative), we're getting this done, and you are bringing her the medicine now." Whether you're liked or annoying, the squeaky wheel gets the oil.

Jessica Queller:

I've learned those lessons. I already had quite an education before it was my own turn. The bottom line is... I don't know. In retrospect when I look back at how young I was, I have no idea how I had the self-knowledge to make those choices. I just thank G-d that I did. You have to be your own self-advocate,

meaning that you have to listen to your own inner wisdom and truth, and have a really strong sense of what's right and wrong for you, and not be swayed because doctors are just human beings.

Jessica Queller:

Nurses are just human beings. Everyone has their own biases. Everyone has their own opinions. These decisions are too important to be guided by anyone but yourself.

Jenna:

How did you ultimately choose the providers you did? That's something that women that we talk to are always struggling with. Which one is the right one for me?

Jessica Queller:

Again in retrospect, I don't know that I did enough research, because I just... Once I made up my mind to do it, I just was like, "Okay." I went to my mother's breast surgeon who I knew because he had taken care of my mother. One thing I can say about him is that he was old-school, and he loved my mom, and I knew he was going to be as aggressive as possible in taking out every speck of breast tissue possible, which does not make for a great cosmetic result, by the way.

Jessica Queller:

I didn't care because I felt like if I'm going to go through this, I don't want... A lot of the plastic surgeons said, "I wouldn't go to this guy because I need a little tissue to make it not look plastic. I need a little more breast tissue." Instead of having a 2% chance of breast cancer, you'll have a 5% chance. For me, that was not tolerable. I felt like if I am going to go through all of this, I don't want any chance. I want nothing, and I don't care if I have ripples.

Jessica Queller:

Again, for someone else, that might not be the case. They might prefer a more beautiful aesthetic. They might be able to tolerate a 3% higher risk for a more beautiful outcome. This is all incredibly personal. My goal was get rid of my risk. I just trusted my instinct, but I only met a couple of doctors, and I really just went with the plastic surgeon who I liked personally. She was kind and lovely, and I went with my mother's doctor.

Jessica Queller:

When my sister went through it, she did a lot more research, and frankly had a much better cosmetic result, but it really depends on your priorities. I'm always about trusting the human. Trusting the person who listens to you, who you feel is respecting your opinions, who honors what you want, and really listens, and doesn't impose their ideas onto you.

Jenna:

Yeah. Through the book you talk a lot about your desire to become a mother, and how that influenced your decision-making process, and ultimately took you on the path that you did. Can you talk a little bit about what happened after the book and how you became a mother?

Jessica Queller:

First of all, as I mentioned to you before we started, I went back and skim read my own book last night because I haven't picked it up in at least eight years. I was like, "Oh, I forgot this detail. I forgot how this went." I had completely forgotten the date, the exact date of my mastectomy, which was September 12th. As it turns out, I am finally getting married on, this is weird, but on September 11th of this year.

Jessica Queller:

I'm reclaiming the date. It's in New York. It's the only date that was available. I got chills when I read that last night, because it will be exactly 16 years after I made that choice. It was always my dream to be a mother. When I was a little girl, I would chase little girls around. The minute I could, I was babysitting. When I was an unemployed actress in my 20s, I was a nanny. I've just been that person. I never dreamt about my wedding. I dreamt about being pregnant.

Jessica Queller:

I dreamt about my daughters. When my mother was dying, which was, again, there's no words to describe how horrific it was, not just physically, but because she was young and she didn't want to die, and she fought her last... Her last words were, "This is against my will." I was so depressed throughout my mother's death that I just suddenly felt like I don't understand. Existential despair. What is the point of life? Writing is fine, but I could take it or leave it.

Jessica Queller:

I don't care about TV. I love my friends. I haven't found love. I was like, "I really am in despair, and I don't understand the meaning of life, and what it's all for." In my darkest moments, I had this little voice inside of me that said, "You need to have a baby. You need to be a mother, because then you'll understand your purpose." I just decided, and then the thing that made me sob reading it again last night is that one of my last nights with my mother when we were in Las Vegas at the ill-fated Celine Dion concert when she got too sick and couldn't go, she was lying in bed.

Jessica Queller:

She for the first time was very calm and said, "I don't have long to live, but I'll always be with you. G-d takes and he gives away, takes and he gives, and he's going to give you a baby, and he's going to give you someone to love." It was so not like her. She was very neurotic and all these things, and she was so calm, and it was so loving. That is what happened. I was on a mission that I am going to have a child, and I want to carry a child if at all possible.

Jessica Queller:

The book narrates my frantic search for love, quickly, before I had to have the ovaries out. It was chaos, and there was this boy, and that boy, and this one loved, but I didn't love him, but maybe I should marry him anyway because he's so kind. There was a therapist who said, "Just marry him. Your options have changed. You can always get divorced later." Everybody had opinions. Somehow I just stopped all the noise and said, "I'm going to do this myself."

Jessica Queller:

"I'm going to go to the sperm bank. I'm going to have a baby myself, and I'm going to have faith that love will come later." Here we are. It took 16 years later, I'm getting married, and my daughter is 11.

Jenna:

That's amazing, Jessica.

Jessica Queller:

A long road.

Jenna:

Yeah. Yeah.

Jessica Queller:

But it worked out. I'm very happy.

Jenna:

That's so wonderful. I think some of us are interested to know, did you choose pre-implementation genetic diagnosis? How did you deal with that?

Jessica Queller:

I was very torn about it, for obvious reasons. Mainly because I felt had that been around, I would have been selected out. For those who don't if you're doing in vitro, they'd have the technology to select the embryos that carry the BRCA mutation and toss them, and only implant the babies that don't. That said, because I started to have a baby, tried to have a baby on my own at 37, and my FSH levels were very good, my fertility was strong, I did not have to do IVF.

Jessica Queller:

I just did IUI, fancy turkey baster in the doctor's office. You can only do PDGs... It's PDG or-

Jenna:

PGD.

Jessica Queller:

PGD. Pre-implementation genetic diagnosis. Yeah. You can only do that if you do in vitro. I had decided if I had to do in vitro to get pregnant, then I would do it. If I got pregnant through IUI, and I did end up getting pregnant without in vitro, so I didn't do it. Of course now I have very mixed feelings about that now that my daughter is 11. I have tremendous anxiety. She has a 50% chance of inheriting the BRCA1 mutation. Now, I might have advised my younger self differently.

Jenna:

Is she aware of this at all, or is it something that's come up?

Jessica Queller:

She aware of it in a very general way. She's very aware that grandma died before she was born, and she never got to meet her grandma, and she talks about that a lot. She's very aware that I had breast surgery and I have scars, because she's seen me her whole life. I never hid from her. I tried to make it very normal. I've always said, "Grandma died, and I did a surgery so that I will not ever get that sickness. You don't ever have to worry about that."

Jessica Queller:

I've tried to make it very natural and good. She knows I wrote a book. She's 11. She hasn't Googled it or she hasn't taken it in. A few times she says, "Am I going to have that operation when I grow up?" I said, "I hope not." I'm on the young leadership committee of Basser, which is one of my greatest prides of my life. I love Basser with all my heart, and I am counting on Dr. Domchek and Basser to find better solutions for our daughters so that there will be better options than this if that's the case.

Jenna:

Yes, yes. We are all really hoping. I think hearing this story, and I'm sure people on this call tonight, it's resonating with them and what they're going to be saying to their daughters. One of the things that you talk a lot about in the book is other women's stories, and how you connected with other women who were going through this. At Sharsheret, our peer support program allows us to do that, and connect women with similar diagnoses so they can support each other along the way.

Jenna:

Can you talk a little bit about the peer support relationships that you had in the book? Why were they so important on your journey?

Jessica Queller:

I've heard Donna is here. Where are you? Is she? If she's here, I'd love to say hello. Donna! I'm so happy to see you. Donna was my first friend. We were going through it at the exact same time. We shared the wonderful doctor, Dr. Julia Smith at NYU. Dr. Smith is an oncologist, but she also was everything to her patients. She was therapist, genetic counselor, connector. She was everything. Dr. Smith set us up on a friend date and said, "You're in the same boat. You're about the same age."

Jessica Queller:

"Donna is a bit younger, a couple years younger. You're both doing this at the identical time." We met. We connected right away. I revisited the book last night, and I also got teary reading about us going to dinner, and laughing about Donna was going to reconstruct herself bigger, and I wanted to be smaller, and we were trading bodies. It was poignant. You have to please understand that I don't even remember my own book because it's so long ago.

Jessica Queller:

I was reading it fresh myself last night, and I read the line I wrote which was, "Here we are, these two young women, laughing and drinking a bottle of wine. Anyone walking past us, no one would have imagined they're talking about removing their breasts next week." It just was surreal. It just meant everything to have someone to talk to who was going through the identical experience. At that time, there really was nobody to talk to.

Jessica Queller:

There was FORCE. There was the FORCE website that I know we both used as a resource a lot, but at that period of time, there were really no young women, unmarried, single women on those boards. It was all women who had already had their children, and they felt their breasts had done their breastfeeding job, and they had husbands, and they felt like they were in different life places than we were.

Jenna:

I remember this one part of the book, and I think Donna goes with you to the meeting at the hospital right after your surgery, and you do a show and tell together. You were the only two women in that room who had had reconstructive surgery, and the difference it made for all those women there.

Jessica Queller:

I remember that. We took our shirts off for a lot of people.

Jenna:

This book was written 13 years ago. Your experience was 16 years ago. What's changed the most since you wrote this book in terms of the field, and women and men who have hereditary risk?

Jessica Queller:

The number one thing that's changed the most, thank G-d, is this is no longer a new or unknown thing. If you're a young woman and you go to the doctor now, the doctor says, "You need to have a prophylactic double mastectomy, and this is your surgery date." If you don't want to, then now you're being the maverick. Then that's your choice, but there is clarity in how successful it is, and how... It's not a big, mushy quandary to solve. For better or for worse, I think that helps.

Jessica Queller:

It helps to be told. You go to an expert, and the expert tells you what to do, and you have to deal with your feelings, and you figure out what to do, but you don't have to navigate it all by yourself like we did. Number two, I have seen a ton of women take their shirts off for me in recent days, and boy, do they look gorgeous. The reconstructive surgery is crazy these days, how beautiful it is. I think that's a really big deal in terms of the trauma of losing your natural breasts, but knowing, "Well, I'll just have to look like a supermodel. Poor me, and they'll be like this forever."

Jessica Queller:

I think that's a really big deal, as well. I wish I could say there had been more advances in options, but as far as I know, not yet.

Jenna:

Yes, hopefully soon. Before we open it up to Q&A, Jessica, we can't have the showrunner of *Supergirl* on our webinar. We're talking just a little bit about your life in Hollywood. What advice would you give for anyone who's interested in breaking out in Hollywood these days?

Jessica Queller:

Oh, my gosh, call me, I'll tell you everything I know. TV writing, the profession has completely changed since I started 20 years ago. TV has had a renaissance. When I started writing for TV, I was a theater snob from New York who was like, "I don't watch TV. I'm just doing this just for some cash to figure out how to support myself as a creative." Now television is... I thought I would segue into feature film writing quickly, and then suddenly the feature film world disappeared and TV became everything.

Jessica Queller:

A lot more people want to be TV writers than they did 20 years ago. It's harder. It's harder in certain ways and easier in certain ways. It's easier in that I think there's so much more content. There's all these platforms. Who can even possibly keep up with how many shows are being produced and aired? There's a ton of opportunity, but it is also, everybody knows about being a TV writer now, and tons and tons of people want to do it.

Jessica Queller:

It's not as glamorous as it looks. From my point of view, it's really hard. It's really grueling and hard.

Jenna:

I still think you're very cool, Jessica. I just want you to know.

Jessica Queller:

Aw. Yes. I don't know what I can say about the Hollywood of it all. There's a lot of special parts, and there's a lot of really grueling, difficult... Before COVID, I think I've lived in Los Angeles for many, many years. My only memory of Los Angeles is midnight on the Warner Brothers lot in an empty parking lot with another writer or two. It's a golden handcuffs. You work really hard on these shows, at least on these network shows.

Jenna:

It sounds all very glamorous and exciting. Thinking about driving around on the Warner Brothers lot.

Jessica Queller:

It was glamorous for year one. Then by year 19, I'm like, "Oh, my God, I have never left this empty parking lot." All I've ever seen of LA.

Jenna:

That story of Harrison Ford who charms your mom.

Jessica Queller:

That's very special because his wife, Calista, has been my friend since we were unemployed theater actresses together in 1991 in New York City, so our friendship predates Los Angeles, Hollywood, *Ally McBeal*. It predates all of that. That's just a very, very special old friend of 27 years or something by now.

Jenna:

Yeah, yeah.

Jessica Queller:

He's a very kind man. Very, very kind.

Jenna:

From Harrison Ford to our Q&A-

Jessica Queller:

He's probably the most glamorous part, Harrison Ford.

Jenna:

Jessica, we have one question here. I think this is so important. Since testing positive for BRCA, there's now known more information about other cancers associated with the mutation. What are you doing now in terms of surveillance for pancreatic cancer and melanoma?

Jessica Queller:

Actually, which Lisa knows, I just went to see Dr. McAndrew, because Lisa Hoffheimer helped me get in to see her. My sister and I went, and we just took the whole updated panel of genetic tests. We'll find out. I'm really scared, but I don't think anything on that panel is as scary as what I already have, as far as I know. I haven't screened for pancreatic cancer yet. I realized that I had been lax in figuring out how to keep up with things, so I just went to see Dr. McAndrew a few weeks back and said, "I want to just get all the tests. Everything. Whatever there is, just throw it at me," and just continue to get...

Jessica Queller:

As the field changes, continue to get as much knowledge as is possible.

Jenna:

Can you share why she recommended that you and your sister get an updated full panel for someone who might have already tested positive for BRCA?

Jessica Queller:

I think that Dr. McAndrew's philosophy, even stronger than mine, is that knowledge is power. She said that... In my book, I think I even write 16 years ago, I was told you can only carry one mutation. That's not the case. Dr. McAndrew told me she has a patient who has BRCA1 and BRCA2, and this new thing. BRCA2 has a slightly elevated... I believe I'm right, someone medical may correct me. I believe BRCA2 has a slightly more elevated risk of pancreatic than BRCA1, even though BRCA1 has slightly worse breast cancer numbers.

Jessica Queller:

If you know you have more than one, then you... If you know you have one with a higher pancreatic risk, then you're going to take whatever pancreatic surveillance exists, and also insurance will pay for it if you carry that high risk. There's gradations of things. It's just better to have all the knowledge.

Jenna:

I know that this might be bringing up some questions for people. Anyone on this call, our genetic counselor is available for you to make an appointment for free to talk through any of this, whether or not you've been tested for a mutation or not. Please just know that. Someone just asked what other gene were you referring to, Jessica, when you said that there was... ?

Jessica Queller:

There's a whole panel of new genes, and I'm not educated enough to say all the names of them. Since I took the test, there's a handful of new mutations. None of them as far as I know have as high of a risk as

BRCA1 or BRCA2 in terms of breast or ovarian cancer. Their risks are lower, but they're still significant, but I don't know the names. I really should educate myself if I'm going to speak about them.

Jenna:

No, no, no, no, [crosstalk 00:47:25] tonight. I just want to add that some of those mutations are quite common. People may have heard of PALB, CHEK2, Lynch Syndrome, which increases risk for ovarian cancer. Every year we're discovered more mutations, and so panels have been increasing over time. Again for anyone on this call who may have been tested in the past or is interested in testing, speaking with a genetic counselor can help you decide what panel test is right for you.

Jenna:

Please keep that in mind. Jessica, why did you choose the title, "Pretty is What Changes?" What does that mean to you?

Jessica Queller:

I write a lot in the book about my mother and my maternal grandmother. My maternal grandmother, Harriet, was an actress in Hollywood. She was in all the old Three Stooges movies. She was in the Dragnet series. She was basically, she played a recurring role in Three Stooges of the French waitress. She was a glorified model, redheaded model who was a girl who got the pie thrown in her face. Now my snobiness is coming out. She wasn't a serious, trained classical actor.

Jessica Queller:

She was a very pretty girl with chutzpah, and she did a lot of Hollywood stuff. Then she was a grand character. She had three husbands, all of whom were gone by the time I was born, and she had one daughter. She was a single mom with my mother. She wasn't a very maternal person. She and my mom used to double date as sisters in Las Vegas in the '60s. The point is that my grandmother and my mother, it was all about women being beautiful. Your commodity was beauty.

Jessica Queller:

Number one most important thing. I was raised with a skewed emphasis on, "You have to be pretty, you have to be pretty." Most important thing. My sister and I were raised that way, and it gave me a lot of hangups because I never felt beautiful enough, and I thought my sister was more beautiful. My sister was like my mother and my grandmother, and all that stuff. No matter how I felt about it, it was ingrained in me that a woman's value is very much in her beauty and desirability.

Jessica Queller:

Now in 2021, it feels very antiquated. I'm old, so that's how I was raised. The idea of... My mother never removed her breasts while she was alive. She had a lumpectomy because they didn't know about her BRCA status. I reminded myself in the book by looking at it last night that when my mother was told she didn't have to have breast cancer... I mean, a mastectomy, she thought it was because of the lymph node involvement, that it had already spread, so there was no point.

Jessica Queller:

That wasn't accurate, but that's what she thought. She said, "Oh, thank God. Thank God it spread to the lymph nodes so I can keep my breasts." When she first got her diagnosis, she would have preferred the

worst cancer because she didn't know what she was talking about. The idea of removing her breasts was horror, horror, horror. Beauty and what it meant for me at 33 and 34 as a single woman, to remove my breasts and have mastectomy scars, and is anyone going to love me? Am I going to ever... ?

Jessica Queller:

For a period of time I felt like my life is over. It's over. I missed it. I'm never going to have love. I'm never going to have family because my mother and grandmother had ingrained in me that if you're not desirable, you're not worthy. That subject was a theme throughout my life, throughout the book. Pretty is what changes is a lyric from one of my favorite Sondheim musicals, *Sunday in the Park with George*. The full lyric is, "Pretty isn't beautiful, mother. Pretty is what changes. What the eye arranges is what is beautiful."

Jessica Queller:

Which means pretty fades like a flower. True beauty is from within, and can be seen only by those who are talented enough to see it. Not many of those in Hollywood, but I found one.

Jenna:

Jessica, we are so blessed to be able to have you, and for you to share your heart and your inner beauty with us this evening. Thank you.

Jessica Queller:

This was so special. Really special to me.

Jenna:

Thank you. For all of you on the call, we do want your feedback. We have an evaluation survey. It's going to be placed in the chat box right now. Jessica has generously offered five personalized autographed copies of tonight's book, so if you fill out our evaluation, you might get one of those copies. Once again, I want to thank the Basser Center for BRCA at Penn for their dedication to genetics awareness and education, and our community partners JScreen, the Minkoff Center for Jewish Genetics, the Norton & Elaine Sarnoff Center for Jewish Genetics, Temple Israel of Hollywood and my hometown, the Victor Center for the Prevention of Jewish Genetic Diseases.

Jenna:

As we close, I know that this conversation might have brought up a lot for the people on this call. I have mentioned our Genetics for Life program, so please don't hesitate to reach out to Sharsheret if you would like to speak with our genetic counselor or if you're interested in peer support, and most importantly to speak to one of our mental health professionals. Jessica spoke so beautifully about her experience about her mother, and how that influenced what she went through.

Jenna:

We know that things are challenging for everybody, so please know that we have a team of mental health professionals that are here to support you during your journey. Once again, thank you, Jessica, for tonight. You're seeing all these beautiful stories come in, Jessica. We'll send it to you afterward.

Jessica Queller:

Sharsheret's National Book Club with Jessica Queller

Send it to me.

Jenna:

Thank you again, everybody. I hope you have a wonderful evening.

Jessica Queller:

Thank you so much, everyone.

Jenna:

Thank you.

Jessica Queller:

Donna, call me! Lisa, I love you. Thank you. Thank you all.

About Sharsheret

Sharsheret, Hebrew for “chain”, is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret's Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer • Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors • Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer • Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

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