Get Personal:

Body Image, Sexuality, and the Impact of Cancer

National Webinar Transcript

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Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

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Contents:

I. Introduction

Bonnie Beckoff: Good evening, everyone. I want to welcome all of you to Sharsheret's national webinar Get Personal: Body Image, Sexuality, and the Impact of Cancer. We are delighted that you have joined us tonight and that so many states are represented. Feel free to ask any questions by typing in the question box on your dashboard on the right hand side of the screen. Please keep your questions brought in nature so that everyone on the call can benefit from the discussion. We will try to get to as many questions as we can after the presentation. Those of you who are not joining us via computer, please know that you can call Sharsheret at any time with your questions and we will be happy to discuss them with you.

My name is Bonnie Beckoff and I am a social worker and the Senior Support Program Coordinator for Sharsheret. I am thrilled to be here moderating tonight's webinar, which I hope you will all find informative and beneficial.

We would like to thank the Siegmund and Edith Blumenthal Memorial Fund and Sientra for their ongoing support, and for sponsoring tonight's program.

Sharsheret is a national not for profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. Some of the information discussed and the images included in the slides are graphic and may be sensitive in nature. We advise all listeners to use their discretion while viewing and listening.

We are delighted to welcome so many of you on tonight's call. Sharsheret is a national not-for-profit organization supporting young Jewish women and their families facing breast and ovarian cancer at every stage. Our mission is to offer a community of support to women of all Jewish backgrounds diagnosed with breast cancer or at increased genetic risk by fostering culturally-relevant individualized connections with networks of peers, health professionals and related resources.

Although our expertise is in young women and in Jewish women, we do offer support to anyone who reaches out to us. Our goal is to connect to our community whatever your personal background, stage of life, genetic risk, diagnosis, or treatment.

Tonight's webinar Get Personal: Body Image, Sexuality and the Impact of Cancer, is something we all think about but don't necessarily talk about. One's body image and sexuality is something personal to each individual. We often hear from our callers about their concern regarding their sexuality and insecurities related to their bodies at different points of their cancer experience. Whether you are at risk or post cancer, in a relationship or single, your treatments may impact how you feel or what you choose to do.

For example, many in our community, using the Mikvah, or ritual bath, can be a spiritual and healing time, whether a woman chooses to use the Mikvah for religious reasons or as healing waters as a woman prepares for treatment or to mark the beginning of healing after the completion of treatment. However, there are many concerns that can arise from using the Mikvah, such as showing one's body in front of the attendant, with scars, losing one's hair and other post cancer treatment effects. We have also heard from callers that using the Mikvah can bring a renewed sense of healing, hope and thankfulness.

For some in the Jewish religion, using the Mikvah signals that couples can reunite intimately, and this can stir up many feelings and insecurities, as some callers have shared their concerns about what intimacy will be like post-treatment. How will they feel? Will it change the couple's relationship?

There can be times when the reconstruction process can also cause difficulty with body image as you are getting used to your new self and learning how to cope with the changes you are experiencing. For instance, we have heard from callers that they may not like the way their reconstruction turned out initially, either by the way it looks or by the way it feels and feel apprehensive about how it will affect their intimate relationships and how it also impacts their femininity. Additionally, studies have shown that many women feel they don't receive enough information and education from their treatment team on the topic of reconstructive surgery and how it could affect your body image, self-esteem and self-confidence and more so, how it can affect your sexual relationships. Tonight, our experts will educate and inform you on these issues and more, so that you can be empowered to discuss these issues with your treatment team and make decisions that are best for you.

We have some great speakers who are not shy to address your questions about the psychosocial and physical concerns surrounding body image, self-esteem, sexuality and reconstruction. We will also have the opportunity to hear from a peer supporter who wants to share her personal experience that will hopefully offer some insight for all of you. Our first speaker on tonight's webinar is Rachel Hercman. Rachel Hercman, LCSW is a psychotherapist specializing in dating and relationships, sexual health, and trauma. She is in private practice on the Upper West Side of Manhattan and is a noted speaker in communities, universities, and professional trainings. Rachel is the Clinical Director of the Layers Project Magazine and has been a featured expert on various websites, including Marriage.com, TheHealthSite, the Better Sex Blog, and YourTango.

We welcome Rachel Hercman.

II. Body Image and Sexuality: Psychosocial and Emotional

Rachel Hercman: Okay, can I be heard? Can anyone hear me?

Bonnie Beckoff: Yes.

Rachel Hercman: Okay. Thank you. We're just getting slides up. Here we go. Okay. Thank you so much. Alright.

Hi everyone. Good evening, at least in New York it's evening right now. It's wonderful to be here and to collaborate with Sharsheret. It is such an essential organization that it's difficult to imagine what it was like before Sharsheret was around and so it's wonderful to be here with all of you.

So whenever I prepare for presentations, I get a nice healthy dose of jitters and some imposter syndrome. And I was once discussing this with a relative of mine and she gave me a great analogy, and she said, so she is someone who has traveled to Italy quite a few times and so whenever she goes to Italy she knows her way around, and whenever family and friends are traveling there everyone knows you call Jen to get tips on what to see, and she told me- people always ask her, you know, what are the big highlights? What are the big attractions? and her answer is I could tell you the big attractions, but just know it's pretty awesome to just walk down the street. And so, these conversations, like the one we're having tonight about our bodies ,about sexuality, about the impact of cancer; yes, we want to talk about the big stuff, but it's also pretty amazing for us to even be having these conversations, which really don't happen often enough or at all. Doctors' offices and hospitals in our communities in our schools as Bonnie said. You know, even at our mikvahs this conversation is very broad, it's so nuanced, it's so complex. We're starting a conversation. We cannot cover these topics completely in the time allotted for tonight. But really the goal is about starting the conversation to give a language to our experiences and just another note that whether you're here because you've been through cancer, maybe you're going through it right now, maybe someone in your life has gone through it or is going through it, maybe you're at risk, maybe you just got your results of your genetic testing last week the topics here tonight having these conversations can be refreshing and can be empowering.

It also can be unsettling and triggering. We're not discussing homemade recipes for making cake pops, right? This is loaded stuff. So I would just encourage you throughout tonight's webinar to be in touch with yourself, to kind of check in with yourself. If you're feeling emotionally dysregulated to kind of take a few breaths have a drink of water kind of maybe notice your feet on the ground. If you need to walk around the room for a moment. It's important for us to be aware of how these topics affect us.

Okay, so if I had to come up with the most common question that plagues people, about a variety of issues, not just about our bodies in about sexuality. It would be the question of Am I normal? And what we're asking that question were essentially asking is my experience shared by others? Right- do other people get it- what I'm talking about. Do other people

understand what I'm dealing with? And it's a very lonely experience. It's a very lonely experience when we're going through something and we're not sure if other people have experienced it as well. Now for non-stigmatized topics, we can pretty easily ascertain whether our experience is normal, right? I live in New York. So I'll give an example of traffic here if you showed up at a wedding and you turn to your friend and you said hey, did you guys also have crazy traffic on the Cross Bronx Expressway tonight? What I mean is, let's be honest, it's the Cross Bronx, of course, and it had traffic, right? So you ask your friend and she goes- yeah us too. The GPS told us we need to take side streets, right? So that's an example of a non-stigmatized topic that we can easily reach out to someone and say hey was this normal did this happen to you as well? The issue is for stigmatize topics or former, taboo topics or things about sexuality, cancer, our bodies; it's much more difficult. And so then, we end up being left to our own devices, literally and figuratively to get validation information and to get that reassurance that our experience is normal.

Not that long ago, there was positive psychology, and it rose as a popular field in the mental health world and it kind of operate on this premise of like we just got to be positive; and as someone that ran support groups, I saw the effect of that because sometimes people aren't given the space or the permission to share- the good, the bad, and the ugly. And I find for a lot of people dealing with conversations around cancer, they're not necessarily given that permission to have this range of feelings about it or people close to them, well-meaning will say things like well at least blah blah blah, you know, trying to find a silver lining. And I always say that if a statement starts with the words “at least blah blah blah”, it's probably not a statement that should be said. I just read last week in the Jewish Action by the OU, their magazine. Rabbi Dovid Bashevkin wrote a great piece and he wrote in it, “Don't tell someone that something is a bracha (blessing) unless you would wish that for yourself” and I thought that was such a great line. So we're going to move along tonight to try to get this conversation to try to hopefully make you feel a little more like what you might be thinking or feeling is something other people share as well.

So sex is something that everyone has different perspectives on it and our perspectives are always changing, constantly changing; and whatever perspective we come in with is very legit and very very valid. And it's just throughout our lifetimes when we add in the conversations with cancer and sex it adds another layer; and our perspectives on our bodies and on sex change as well. So for the next few minutes, I want to talk a little bit about some of the common things that come up for people regarding their bodies regarding sexuality and also get an understanding of some of the myths that we come in with. Because if we have a house that experienced damage from a storm, it's very helpful and important for us to know- What was the baseline before the storm. Right? And that gives us more of a picture.

So even talking about, you know, people often when it comes to relationships and sexuality and their bodies they want tips, right? How do

I fix this? I got- I have this -I have that- how do we fix it? Tips are very helpful. But I also find that if it was easy to just do it, you would have done it already. So it's also helpful to look at our thoughts and our feelings around these topics too.

So what is body image? Okay. So it's how you see yourself in the mirror, how you picture yourself in your mind, how you relate to being in your skin. Now, there are a lot of people-their weight and their number on the scale is very very connected to how they feel about their bodies. If they see a number on the scale that is not a number they like, they feel really terrible about themselves or how we look in the mirror. It's very interesting little kids, I find, if you look at little girls playing dress-up and they're dressed up as princesses and a little girl says to you-“don't I look gorgeous?” Right? So very often with little kids’, say that we're like, yeah, you look beautiful. Right? We don't then turn to someone next to us and say oh my gosh Sophie is full of herself. She think she looks so pretty right? And yet somehow, unfortunately, along the way, on the road to adulthood we start to develop these insecurities or that it's not okay to love our bodies or to feel good about our bodies.

And sexual self-esteem, which is very connected to body image, how you view yourself as a sexual being, beliefs about your sexual appeal, feelings about sexual competence; what you bring to the table right, your value, I think a lot of us- we strive to have this but we often feel more shame. If you look at little kids, little kids don't have a lot of shame about sex. If you've seen young children who are let's say pleasuring themselves sitting on the couch and we want to explain to them, there's a time and place to do that. Right, little kids don't have shame about having an orgasm because it doesn't mean anything to them yet. It's not an institution yet. So that’s just helpful to kind of ask yourself. I mean even just the idea of what does it mean for me? What does it mean for me to be a sexual being- is a really helpful question to ask ourselves; because very often for women, it's not a question that we are encouraged or kind of even just embracing that growing up. It's not necessarily something that women are kind of supported in and doing.

So all of our personal stuff, these are things that are in our suitcase because we all have baggage. These are things that we all have about sex, love, marriage, such vulnerability. These are things that affect how we view our bodies and how we view sex. I think when we are talking about cancer, there's an added complication to this because, how you looking at our families and say, how does Family talk about illness. How does our family talk about our body's changing because of cancer. How does our family talk about breast? How does our family talk about sex or feeling sexual or sexy? Right? These are all things that that play a role in to our concept.

Experiences during our formative year’s right-this also I think affects a lot of people, because, I think for many young people many young women, they learn when they get their period that you know, this means your body's going to be able to have a baby one day and right it's in a very simplistic way, and for women who are dealing with cancer or finding out

that they're at risk that kind of challenges that whole thing, that kind of perfect picture that a lot of women have as young girls about what the future may bring.

Body awareness- I mean we could speak about body awareness for hours. But what does it mean for me to live in my own skin? Can I be present for my body? Right, there is a value to us being checked out from our bodies and living from the neck up. Think about like a day or let's say you had so much going on, you had such craziness. Maybe it was a Friday- you were preparing for so many things and you realize that its 3'oclock and that you didn't eat lunch, or if you're a parent with young children and you were woken up at 3 a.m. And you're up in this kid threw up and this kid did that and by 7:30 a.m., you realize "oh my gosh- I've had to go to the bathroom for the last three hours", right? So there's actually a value sometimes for us to check out or be able to check out of our bodies. But when it comes to feeling good and vibrant in our bodies and feeling connected to our sexual selves and experience sexual pleasure, being checked out of our bodies can sometimes cause complications, right? I like to joke how we host a housewarming party in a house you don't live in. right. So even just the body awareness of what does it mean for me to be out of my body, is a big question for a lot of women, okay.

More personal stuff that gets in the way: our role models. Who are the relationships that we'd like to emulate right? This affects our sense of our bodies and our sexuality to culture. This is also I find plays a really big role. Right- who is in your community, right, who are the people that give you advice, or support you, or give you a sense of normalcy about what you might be going through. This is especially significant when it comes to conversations around cancer because in different religious communities, there are different norms and different nuances about speaking about it. When I first graduated I had a job in Brooklyn. I worked with a lot of people from the Yeshivish and Chasidish communities and there sometimes cancer would just be referred to as a "machla" and not really any more details or sometimes not spoken about it all. And even in the Centrist Orthodox Community. There are people that choose not to talk about it. So every Community has its own kind of nuances about how we feel. I didn't talking about it, but even within certain societies, right how we speak about women's health and things like that.

Media also plays a very big role when it comes to our bodies and sexuality and the influences of that. I mean even Angelina Jolie. When Angelina Jolie wrote an article and I believe it was 2013 about her choice to get a double mastectomy; her mother had died of I believe breast cancer and she opted to get a double mastectomy and she also wrote about it and they say that within a few months after her article the rates of people going for testing, genetic testing, skyrocketed like a huge jump. And it's interesting because she actually in her article in the Times, she wrote it in the New York Times, she said that for her she doesn't feel any less feminine, and I think it's great that she wrote the article because by doing so she opened up conversation. But there are plenty of women who

do feel less feminine through these experiences. So the media also plays a role of kind of comparing ourselves to what other people might be presenting.

So now we have a lot of myths that we carry about sex. Why is it that we often can you know believe these things that may not be accurate? So one there's absence of conversation, right? If we're not hearing accurate conversations at home or you know, in other places than what we could easily see we could easily believe what we see and there's also you know, the influence of repetition and real life is hard work, right? So it would be nice if what we saw was true.

So myths of good sex: so in your average portrayal of sex in a movie or a book it goes something like this- it's a man, it's a woman, they get turned on at the same rate, their arousal rate seems to be the same, when they get to intercourse his penis slips right in it doesn't slip out at all, he thrust in and out they climax together at exactly the same time. Like they're like synchronized swimmers in the Olympics. There's no lubricant, there's nobody passing gas, no one falls asleep in the middle. There's no cleanup after and there's no towel to grab. There's no child walking in, in the middle. And if there was a child walking in, it would be considered a comedy. And I've yet to see a time where a woman is then laying there afterwards and says, oh, let me go pee so that I don't get a UTI, right? So the images that we see in movies are generally not that accurate. So here are just some common things that come up: that sex should happen spontaneously and without any work, people who love you should intuitively know what feels good for you, everyone is having better or more frequent sex. This comes up for a lot of people. No one is having good sex, neither can you. Other myths of good sex: married sex is always magical and well worth the wait. Good sex is for people with young toned bodies. I mean that also comes up. I was actually reading, there are a lot of studies that talk about women's confidence overtime, and one of them was talking about how for women, even if their body changes as when we get older, they care less about what people think and have more confidence within themselves. And as I read that study the first thing I thought about was the Lohman’s dressing room and if you've been to the Lohman’s dressing room, you know exactly what I'm talking about. The Lohman’s dressing room was this large room where women, who at the time when I was a teenager, seemed like they were old but they probably were not very old, and they're all trying on bathing suits and all of us teenagers were like, “whoa-no way!” We're all standing on line for the one dressing room and our moms are telling us, “What’s the big deal come on”. Anyway, so I was happy to see that there is literature out there suggesting that as women get older, they do feel better about themselves sexually.

This is a common one that men are sexual beings and not women. This is big because what this does is, women that feel ashamed to talk about sex, to initiate sex, to complain about their libidos. Whereas men, if they're told you're just a sexual being and it's difficult for them to talk about their emotions sometimes. If you are not having good sex there

must because emotional issues causing it. You know, this is big because you know, if your whole life you're told okay, it's all in your head your feelings about having sex are all in your head and then you go through physical interventions related to cancer and your sex life is definitely affected by it. So it's obviously not just emotional issues, but if nobody is talking about it, how do you even know like where to turn?

Sexual desire- right it's all in your head; desire always comes before arousal. This is a big one which that model, that sexual response model, was from the 70s for many women desire does not always come before arousal. Emotional connection should naturally leads to sexual desire that you know, if we're best friends, of course, we're going to want to have sex with each other for many people that's not the experience. If you're happy in your relationship you shouldn't experience sexual desire for anyone but your partner- this is a common one that comes over people too. The truth is just because we're married doesn't mean we're dead. And so we're still going to notice other people. We still might feel attracted to other people. And again a lot of this is about how comfortable people feel being touched, being in touch with themselves, and their sexuality.

Myths of arousal and orgasm: If you get nothing else from tonight, even just this one idea that orgasm is a natural outcome of intercourse; I mean that is so common that misunderstanding. The studies seem to show over and over that about 75% of women don't have an orgasm from intercourse alone and have an orgasm from clitoral stimulation. But because it's not talked about often, a lot of women think they're the only ones who have that experience.

Couples should always organs orgasm at the same time, which I think adds a lot of pressure to the situation. The idea of lubricant use- it's actually pretty normal really common. That were supposed to be multi-orgasmic- I find for most couples in long-term relationships, it's just not realistic at all to expect that in one night that you're going to be multi-orgasmic. That orgasms are super loud and that it only counts, our sexual experience together only counts if we have an orgasm. That happens for a lot of people too.

A lot of myths about vaginal pain: it's all in your head, that it's normal for to be painful for the first year of marriage, must be because you're religious. Sometimes people in faith communities get this as well and I don't have time to go into all these and more details, but I want to throw this out there because I think a lot of people have these misunderstandings about sex, and it's helpful to understand. Like I said, if a house is going through a storm, it's helpful to know kind of what was the Baseline before what was it like before then?

So let's talk a little about the impact of cancer and body image and sexuality. And again this this topic there's so much we could talk about we could talk about it for hours and hours and hours, but really just about starting the conversation.

So for one thing you start to relate to your body differently now, right, you might feel scared of what's happening in your body scared of what could happen in your body scared of what has happened to your body. Your body also becomes the focus right? You're going to doctors; you are constantly having conversations about your body. You might hear your body summed up in very simplistic terms. You might feel defective right from a genetics perspective. Right? Some people feel very defective. You're also having people make comments to you on your body. You know, if you I sometimes notice how if you look at little kids when little kids greet each other, they don't really comment on each other's bodies. They just kind of had this authentic like “Hi, how are you want to come play”. And women I find often when we meet up with each other, one of the first things we comment on is bodies. Oh your hair looks awesome, or I love your shoes or things like that. So already, bodies are a big focus of our conversations, for better for worse. And so now you're also dealing with cancer which adds complications to it in that regard. I also find that for many women and I think we all have experiences where something happens to you and you know, as it's happening to you that this is a line of demarcation in your life between what was before this point and what will be after this point. And no matter what your outcomes are and how great things or prognosis, things like that, you just know that this experience is a new before and after for you and for a lot of women when it comes to their bodies that is something that they feel very powerfully of this real before and after.

Cancer really changes things that many women feel makes them feminine, you know, losing hair changes in your breast your weight changes, you know menstruation the potential or ability to conceive. Cancer has a way of kind of hitting everything on a bingo board if we made a bingo board with every sensitive topic for a woman, cancer hits every single box and the body tells a story that story is now eternally part of you, right and that that that's a big part of this impact, too.

Other impacts right: changes in breast and nipple sensitivity, right this can happen for a variety of reasons. Whether a woman let's say has a mastectomy or during her treatments on the next slide I want to talk more about some of that. But for many women and I've heard from many women, that stimulation of their breasts and nipples during sex was a big source of pleasure for them; and so part of their grief were changes in that regard. Lymphedema- which you know is the swelling, the fluids, right that can also affect women's experiences with sex. Surgery, physical and emotional traumas, its scars, right scarring. Also for some women, they're getting a series of surgeries. So there's also just that piece of it being in between. There are some women that have I've worked with who have had issues that happen during the surgery so there's some trauma there. Those scars can be, you know, sometimes actually painful scars or just even if you feel like you're over on the other side, but every time you look at a scar it's a reminder that can also play a role or questions from other people.

Okay, anxiety, depression, PTSD, social isolation. This comes up for a lot of people. Right anxiety is basically a reaction inside of us to a perceived threat. Okay. Well, we're having the conversations around cancer right, where it's a very threatening conversation for us. It's very common for people to help people to experience a sense of anxiety. Sometimes that anxiety or hyper-vigilance about our bodies could actually be life-saving. Right because we were nervous about something we then went to go get it checked out, right? So then what do we do with all that anxious energy moving on. It could be depression, PTSD- post-traumatic stress disorder, and social isolation, also comes up for people because let's say you're in a space where you really don't feel like talking to everyone about what you're dealing with but it's also a lot of work to be fake. It's also a lot of work when people ask you how you're doing and they're people who are close to you and they ask you how you're doing and you want to tell them but you don't want to burden them, but you're going through all this.

Also, if the changes happening for you from your treatments, are affecting the way you look, you may not want to be out in public and have people making comments, “Oh my gosh, like your wig looks great” and they might be trying to make to make you feel better, but it's possible that you just want to feel like a regular person. A lot of women struggle with: who do I tell, how do I tell them, and I think just to put a plug for Sharsheret, I think that's where Sharsheret plays such a special role, because a woman can then have a community so to speak of support, and have help but not necessarily feel like she has to tell every single person in her life that she is dealing with this, okay.

Now what other impacts? I mean we could talk about this for hours and hours. There are so many ways that these things affect our sexuality in our body image. You know losing our hair; even with chemo some people get mouth sores, right you're getting mouth sores. Some people would feel like they don't really feel like having sex, right, fatigue, memory loss, or nausea, or vaginal dryness, right? Some people have taste and smell sensitivities. Our nerve endings could be affected, our concentration, right. And concentration is actually relevant, very relevant for having an orgasm, so that can also be affected as well.

In terms of just swelling or redness with radiation; you know, what even just you know, even some of these medications like tamoxifen, even some of these medications sometimes, what's complicated besides for what the side effects can be from taking them all; but also what it means to be able to not take other medications. Without getting into it too much, but sometimes certain medications mean we can't necessarily take certain other medications. I'm not, I don’t want to get into the details about it, but again, it opens up all these other things that could be complicated.

And menopause I mean menopause when it's not through surgical ways. In other words if a woman goes through menopause in let's say her 50s and she starts perimenopause in her 40s. It's more of a gradual process, there is usually like a fake-out break out, she'll bleed for you know, not get her period for 8 months and then all of a sudden start bleeding, and it

turns out she's not a menopause yet. When a woman goes through a more traumatic menopause, through a surgical menopause, it's not gradual. And so the effects can be more felt and palpable and also if you're going through menopause and your peers are not going through menopause. In other words, if you're a woman in your mid 30s or even early 40s and you opt to, you know, get a hysterectomy or oophorectomy, or whatever it might be and you don't have peers necessarily who understand what you're going through. That's again, why also Sharsheret is so important in that way. I am just looking at the time…Change of fertility and birth control options. This is really significant because some birth control options are not a safe option for some women because of hormonal reasons. And then even just changing fertility options of how you have a baby. If you're going to try the IVF route, if you feel like at this point it or if let's say I'm just thinking of an example. Like let's say you have a woman who, she wanted to have three or four children, and it made sense for her to stop after two, right. It was a conversation that she had with her specific doctor that she stopped after two, and gets surgeries, right. So even now for some women that can be devastating and yes, she has children ready, but for some women when that choice is made for you or doesn't feel like it's it doesn't feel like it's on your terms that could be incredibly painful on how you feel about your body and how you feel about your sexuality.

This is a big one for people, right- living with waiting right for results, for outcomes, for next steps. This is really really big for people because we're often waiting for next stuff and it's learning to kind of how I live in between that.

Also the effect on our partner's right. Navigating periods of sexual abstinence, destructive routine, diminishing foreplay; so much of your conversations during the day might be about other things related to your illness or other things about what's going on, not necessarily have sexual contents or space for that. Shifting roles- if one person is more in the caretaking role that can also affect the dynamics. Concerns for discomfort and pain- if one person is very very concerned about the other person, you know being in pain that can also affect their dynamic sexually.

Other affects challenges communicating right? How do we communicate about the changes that have gone on right now. Reactionary sexual dysfunction with a partner could come up to, right, especially if they're fearful of causing pain. Complexity of niddah and mikvah, which was mentioned earlier, but I think what comes up for people too, is that when you're struggling sexually I find that when you're struggling sexually, niddah and mikvah, could be very very triggering for you; because what are you counting up towards? What are you looking forward towards?

And there's a lot of grief in all of this stuff. There's a lot a lot of grief for how it was or how it will never be and coming to a place to be able to accept that. Even for dating right? Let's say you're in the dating world; how do I balance this? How do I how do I share this with people that I that I'm at risk for cancer, right? When do I bring it up? How do I bring it up? If you're in a certain religious circle where you're encouraged to kind of

keep it quiet perhaps. Confidentiality-if I do decide to disclose it to somebody, will they repeat it or let's say some people in my family are deciding to keep it very quiet and keep it a secret, but by me sharing it with a partner I might be then sharing stuff that people in my family don't want to share. And again going back to the fertility and the family planning conversation, and the rejection that if let's say the relationship doesn't work out, it can feel extra loaded if these conversations had come up around cancer. Okay, I'm putting up this side up even though we don't have time to go through it. But I am putting it up because I want people to be aware that there are treatments out there to support people through difficulties around sexual functioning and their bodies. It's not always easy to find treatment or to know who to ask but it is out there and I know that Sharsheret is aware of this stuff as well and they are great great resource for women dealing with different changes that could be affected by cancer or being at risk for cancer.

And then just to kind of wrap up, I just want to mention triggers. Triggers I find are important for people to realize because we all have different triggers for things. Triggers have a way of like, I think of triggers I think of it, like they kind of hijack us like we might have been feeling fine about something and then you're walking outside you're going about your business, you're having a good day and then all of a sudden you realize today was an anniversary of when you found out some news or let's say you heard that that of friend passed away from cancer or I don't know; triggers can often they hit us so quickly. So this is where it's very very important, when it comes to our bodies, when it comes to our feeling of being sexual and all the things that could affect us to really be aware of what our personal triggers are.

I'm going to skip the last one, but I wanted to wrap up with this and say, you know recovery; these are two definitions of recovery: a return to a normal state of health minor strength or the action or process of regaining possession or control of something stolen or lost. For number one I would say it's a return to a new normal for many women. It's a new normal and it's helpful and important for us to keep that in mind. Then the other piece is that there are a lot of losses that come up with the conversations around cancer. So there could be a loss of innocence, loss of safety, loss of optimism, loss of time, loss of confidence, loss of abilities, right? And so a lot of the work around recovering is being able to find a way to connect to those parts of ourselves that feel exiled or that we feel disconnected from. And the topic, I mean the title for tonight's presentation was "It's personal" and the truth is this whole process of recovery, this whole process of cancer, and being at risk for cancer, it is so personal. And so people will say, "am I normal", but we all have our own sense of normal. And yes, it's helpful for us to hear other people's experiences, but it's also important for us to understand that we each are very unique and how we deal with things and being able to honor and accept that too. And also to just remember that we're always recalculating. It's constant, we are always recalculating and this one of the challenges in life and that's why it's so helpful for us to realize that we don't need to do it by ourselves and to enlist the right committee and the

right people who can help us. And that's why we're really really lucky that we have organizations like Sharsheret, to help us through. So with that I wrap up. Thank you so much.

Bonnie Beckoff: Thank you so much, Rachel, that was truly very informative. You touched on so many topics, that I know that I and many of our participants tonight are really walking away with greater knowledge and understanding. I know the points of empowering and triggering words and triggering ideas that you spoke about were really informative and walking away with greater knowledge and understanding of how one self-esteem may be impacted by cancer and for dispelling many myths around sex, and I really enjoyed your use of metaphors. So, thank you so much.

III. Body Image and Sexuality: Reconstruction

Bonnie Beckoff: It is now my pleasure to introduce our second speaker, Dr. Aviva Preminger who is here to discuss the ins and outs of reconstruction with all of us and the impact they can have on body image and sexuality.

Dr. B. Aviva Preminger is a Board Certified plastic surgeon on the Upper East Side of Manhattan specializing in aesthetic and reconstructive surgery of both the face and body and a member of the Sharsheret Medical Advisory Board. She holds a BA from Harvard University, an MD from Cornell University Medical College, and an MPH from Columbia University's Mailman School of Public Health. She completed her postgraduate surgical training at Cornell and Columbia and did a research fellowship in breast reconstruction at Memorial Sloan Kettering Cancer Center. She also studied at the Art Students League of New York. She is past President of the New York Regional Society of Plastic Surgeons and serves on the Board of the New York State Society of Plastic Surgeons and of the American Society of Plastic Surgeons as well as the Medical Advisory Board of Sharsheret. She has been an active Sharsheret volunteer hosting an annual Bagels and Botox fundraiser. She has been featured in the New York Times and New York Magazine's Top Doctors as well as People's List, New Beauty, New York Lifestyles, Bella Magazine, Haute Living, and Essence magazine. Dr. Preminger is a key opinion leader for some of the leading plastic surgery technology companies and oversees ethical practices for the American Society of Plastic Surgeons. She has lectured at national meetings and is in charge of the aesthetic component of the Plastic Surgery Educational Network, educating her colleagues about the latest plastic surgery techniques.

Welcome, Dr. Preminger.

Dr. Preminger: Okay. Well, thank you so much for the introduction. All I'm thinking about right now is that Loehmann's dressing room; I remember very well. So the topic I will be discussing tonight is about what I call the road to restoring what has been lost. And I think that you know, when we talk about breast reconstruction after mastectomy, there is so much information that I think, we a lot of times, as patients don't even know where to begin or what

questions to ask. You know, they just had a breast cancer diagnosis and they're still digesting that or they're digesting the knowledge that they are BRCA positive, and you know now they're considering a mastectomy and they're trying to figure out you know, what the next steps are. And I think that sometimes initially when they come in, they're just very overwhelmed and there's so much information to process. They're not even sure where to go. So I hope that tonight, what we can do is give a little bit of an introduction into the whole reconstructive process and then also go ahead and if you if you're already in the middle of the reconstructive process, to give you an idea of what else is coming down the line

So Gaspare Tagliacozzi, which is my next slide, is widely considered one of the fathers of plastic surgery. And what he used to say was, “We restore, rebuild, and make whole those parts which nature hath given, but which fortune has taken away. Not so much that it may delight the eye, but that it might buoy up the spirit and help the mind of the afflicted.” I think that these words from the 1500’s, are so applicable to the field of breast reconstructive surgery.

So next, when we start to talk a little bit about breast reconstruction, it all starts with the type of a mastectomy you have. So before a plastic surgeon can actually give you what your options are going to be, one of the things that factors into that is what kind of a mastectomy are you a candidate for and the history of mastectomy is. I'm not a breast cancer surgeon; I do just the reconstructive part. But the history of mastectomy is basically that early on a famous surgeon named Halsted believed that you needed to be very aggressive in removing all the tissue of the chest wall, including a lot of the muscles and that was considered a radical mastectomy. And that's what the early mastectomy entailed. But with time, what we've learned is that this doesn't actually determine survival. And so we've been moving more and more towards being able to spare more tissue and give a more cosmetic result and less of a deformity from the mastectomy. And so there are skin sparing mastectomies which basically mean that we're removing the breast tissue but leaving behind a lot more of the skin and all the muscles, etc. And now we have a nipple-sparing mastectomy, which has become more and more common. A nipple-sparing mastectomy will actually allow you to spare your nipple. So in terms of incisions, these are some of the skin sparing incisions that are done and you can see they all remove the nipple areola complex. The areola is the pigmented part around the nipple. This gives you an idea of some of the different incisions the surgeon may use to perform your mastectomy. Some of this is based on surgeon preference and some of this is based upon your own body habitus where the tumor actually is- to allow the breast surgeon to have the access that they need.

Nipple sparing incisions: there are a number of nipple-sparing incisions that can be used and you can you can see them there and that determines some of the scars. The real question though in terms of am I a candidate for a nipple sparing mastectomy, often again depends on the size of your tumor, the location of your tumor, and how large your breast is, and where your nipple position is actually sitting on the breast.

So when we talk about reconstructive options, once the mastectomy is done, there are a couple of different options available. One is autologous reconstruction, which actually uses your own tissue and may involve microsurgery. The next is implant based reconstruction, and I'm going to talk about that as well. And the third is implant based reconstruction which is with fat grafting which the ladies at Sharsheret asked me specifically to talk about that because they get a lot of questions about that now. This is a little bit of a combination procedure where were using some implant and some of your own tissue.

So autologous reconstruction, when we talk about using your own your own tissue to do reconstruction, there are several options available and these are the most common. So most commonly you are looking at some sort of abdominal tissue harvest, to recreate a breast or buttock tissue which is the gluteal flap, the litmus flap which is back tissue, or what we call an ALT- lateral side flap, which is a thigh based reconstruction.

So this is a diagram to give you an idea of what the abdominal flap involves. The traditional abdominal flap actually involved using your rectus muscle, one of your abdominal six-pack muscles, and elevating the whole thing. The problem with it while it is a nice procedure in terms of reconstruction and restoring, the shape and volume of the breast, it gives you what we call a donor site morbidity, which basically means that you are at risk for developing a hernia and also, you know less able to for example do a lot of stomach crunches. So what we've moved to from that, is actually something called the deep flap, which is a deep inferior epigastric perforator flap which actually spares as much of the muscle as possible, and still allows for that reconstruction and that is done actually as a free flap. So what happens is that the breast that the abdominal tissue is actually removed with a blood vessel and that blood vessel is actually hooked up to a blood vessel in the chest region or the underarm; and that involves microsurgery. And this is a gluteal flap which is also a micro surgical procedure. So what happens is the buttock tissue is elevated and similarly used to reconstruct the breast. This is a good option in a patient, for example who just doesn't have enough abdominal tissue, but has buttock tissue available for harvest .The back flap is the latissimus dorsi flap and the reason it's called that is based on your latissimus dorsi muscle, which is one of your back muscles. This reconstruction is often combined with an implant itself and it's often actually used just for coverage of the chest or the breast in patients who have had radiation and have a lot of damage to their chest wall. The side flap, which is also one of those free microsurgery flaps which uses side tissue to reconstruct the breast and hook up those blood vessels.

So now that we've finished talking a little bit about autologous or using your own tissue reconstruction, I want to talk a little bit about the other option which is implant based reconstruction. Implant based reconstruction traditionally was using something called an expander, which is basically like a balloon. It's almost like an empty implant and it has a little magnetic port in it. It's placed usually at the time of the mastectomy. And then what happens is the patient comes back at their

subsequent visits and it's slowly inflated. Because what happens after the mastectomy is that chest wall, tissue, that skin that's left behind from the mastectomy, actually contract and shrinks down. So what we need to do, to be able to put an implant in, is re-expand that tissue to make space for the implant. So that's the way things were done traditionally. Now, we've moved more and more if possible towards something called a direct implant reconstruction, which for the right candidate actually allows us to put an implant in at the time of mastectomy. And we have a come so far because the traditional thinking was actually that a woman should get used to the idea of not having a breast. Now you can imagine how traumatizing that was, but traditionally, I mean plastic surgeons who are initially mostly male, kind of felt, well, we're not going to be able to give them back exactly what they lost, so let them get used to the idea of having nothing and then we can give them something back that they'll feel good about it. That is a very very antiquated way of thinking about things and we've come so far in really wanting to be able to give back what patients have lost or even sometimes, I'm able to give them breast that look nicer than what they've lost which is really really important. The other thing that we talk a lot about that that'll come up sometimes in a consultation with a plastic surgeon with regard to implant reconstruction is whether we're placing the implants in a sub pectoral or pre pectoral position. The pec muscles are those chest muscles, and traditionally we put the expander or the implant underneath that muscle. But now actually there's more use of something called acellular dermal matrix, which is cadaver tissue and that can be used to kind of help cover the implant and avoid placing it under the pec muscle. I'm going to talk a little bit more about that and then also the idea of combining fat grafting adding fat grafting to the reconstruction to help camouflage the appearance of the implant and make it look more natural.

So with implant reconstruction and I think this is helpful to sort of understanding what I was talking about with acellular dermal matrix, which is that cadaver skin; when you look at the chest wall underneath the breast, under the skin you have that pec muscle and you can see in this diagram the implant can actually be placed underneath that muscle, as in “a” or it can be placed above that muscle as in “b”. But often if we are doing that, what we want to do is, we want to get coverage of that implant and use that cadaver tissue either as a sling and it to be partially help cover the implant that isn't covered by that muscle or to cover the entire implant under the mastectomy skin flap that have been created by the breast surgeon.

So when we talk about acellular dermal matrix and why it's used, it is cadaver tissue that helps protect the implant from the skin while the skin that's traumatized, because the breast tissue is removed is still healing. This has recently gotten a little more complicated because the FDA actually took away the indication of use of acellular dermal matrix or cadaver skin for breast reconstruction, which is really unfortunate and it really had nothing to do with the actual safety of the cellular dermal matrix or applicability in breast reconstruction, but rather it had to do with some studies that the companies had promised to do for the FDA and they

hadn't done them in a timely fashion. So hopefully that FDA approval is coming back but I don't know any surgeons who stopped using it. Instead some of them including myself will actually just provide the patient with a separate consent to let them know that officially it's now being used.

Drains are also something that patients ask me a lot of questions about. Drains are very annoying but they're sort of a necessary evil in the sense that drains prevent fluid from collecting within the breasts. And what happens is that anytime surgeons create a space by, for example, removing breast tissue during a mastectomy, the body wants to fill that space with fluid. So we put these drains in so that that fluid can be removed and so that the mastectomy skin can actually heal down against the underlying tissue. Now patients always ask me, how soon can my drains come out because they want them out. Well that all depends on how much fluid your own body is actually putting out. I think most surgeons including myself go with a 25 to 30 cc's in about 24 hours for a day or two and that's usually the point at which we get them out.

So reconstructive timeline-and this is really really important because I think it gives patients an idea of kind of where they're headed. So, you know in the initial consultation-are we talking about an immediate or delayed reconstruction. These days, we always try to do some kind of an immediate reconstruction if we can, but unfortunately if a patient has very advanced cancer, sometimes we have to wait and delay the reconstruction. Also, for example, if the patient is smoking, I'll tell them we can't do the reconstruction right now; it's a too risky and you're not going to heal. You've got to quit smoking and then you can come back and do this. When we talk about autologous reconstruction, its one stage to create the breast mound using your own tissue, direct implant is one stage to create that breast mound using an implant. As far as the expander is concerned, it usually takes about 3 months to do the expansion and kind of fill that expander slowly to get to your goal volume. And some patients want to be bigger than they were before and some patients don't want to be as big as they were before, but it takes about three months and then you go back to the operating room to exchange it for a permanent implant. The exchange procedure is usually an outpatient procedure, and much less uncomfortable than your initial mastectomy procedure. Chemo and radiation can affect the timing of this exchange. If you're getting radiation, then some surgeons prefer to expand you as quickly as possible and do the exchange as quickly as possible. Others will expand, have you do radiation, and then we'll do the exchange and some surgeons won't do any implant based reconstruction at all. Ideally, in a patient who's getting radiation and then chemo for any kind of surgery, we need to make sure that all of your counts have rebounded, so that we know it's healthy to proceed with surgery. As far as the need for revision or adjustment of the breast pocket, I usually say to patients or I prepare them for the fact early on, that this is not just one stage. You know, we will often require revision or adjustment, and I'd rather prepare them for that and have them not need it, then tell them this is going to be one and done and they're not going to need anything again. Often when we come back for revision or adjustment, I'll add some fat but we need to

be able to get it from somewhere and it needs to come from you. Unfortunately, we can't take it from someone else. I often have you know mothers and daughters that sort of a thing and they're like, well can't you take my fat for so-and-so but no, it's got to be your own fat. And then if it is a unilateral or one-sided reconstruction, I will often be taking the patient back and doing like a lift procedure or reduction procedure on the other side. We don't usually do that at the time of the initial mastectomy.

Nipple areola reconstruction usually happens about three months from the final breast mound procedure; and that's if the mastectomy was not nipple sparing. The nipple areola reconstruction is not pigmented so often you have to a tattoo for the pigmentation afterwards.

So fat grafting, this is just a picture of a diagram of how the fat grafting is done, we do liposuction and then we process the fat in a sterile container, and then re-inject it. So you can take the fat from the abdomen or the hips from where you don't want it to be, and are able to put it back where you do.

Nipple areola reconstruction- ideally, there are different methods for doing this. My preference is usually to use local tissue on the breast itself, to be able to recreate the nipple complex. But some people do use Skin grafts and they can be taken from different parts of the body. Traditionally, they were actually taken from the groin area. That's not my preference just because I try to stay away from generally intimate areas. You know, we've kind of traumatized the breast and the last thing I want to do is, you know, create further unnecessary scars elsewhere. And then as far as the tattoos are concerned some patients just say, you know what? I don't even want the tissue based reconstruction. I'm just going to get a tattoo by a real artist and the shading of it'll look like a nipple.

So advantages and disadvantages of using your own tissue versus using an implant. So autologous reconstruction, it is your own tissue. There's no risk of having any device based issues, like rupture malposition or something called ALCL which we're going to talk about and is a breast associated lymphoma. There are also fewer stages usually to the autologous reconstruction, but the implant surgery is a shorter surgery and there's no donor site that you have to worry about because we didn't take anything from anywhere else on your body. We don't have to worry about you having usually a particular kind of build or body habitus and it's often easier in general, and this is true of autologous and implant based reconstruction, to achieve symmetry and bilateral cases. A lot of patients don't have enough tissue of their own to do a reconstruction on both sides and give them enough volume. Disadvantages of autologous are that it is a longer surgery, you have the donor site and the disadvantages of the implant is that you can have potential device based issues.

So ALCL is a rare form of lymphoma. I wanted to talk about it because it is something that's been in the news a lot. It develops adjacent to the breast implants and it's not breast cancer. It is associated, as far as we know with textured implants, and it has not been identified in women who have only had smooth implants. But there is a question of whether it is

possible in women who've had a textured expander that's been exchanged for a permanent implant. The most common symptom is a swelling of the breast and it's due to fluid that's actually accumulating around the implant. So this is the difference between a textured vs. a smooth implant. The smooth implant is on the left and the textured implant is on the right. So most women who are diagnosed with the disease are just treated by removal of the implant and the capsule, and here's some information on where you can go in terms of the FDA or the American Society of plastic surgeons to get some more information on this. I'm no longer playing placing textured implants. I haven't placed in for my cosmetic or reconstructive cases in a couple of years once this information kind of got out just to be careful.

So these are just some pictures that I'm going to run through quickly for the sake of time to give you an idea of the difference between an autologous reconstruction and implant based reconstruction. But also to give you a sense that a really nice reconstruction can be achieved both methods and that the important thing here is that you go to a surgeon who's going to present you with all of the options that are best for you and make an informed decision.

So this is, I do not do autologous base reconstruction. You can't really be all things to all people as they say and so I do implant based reconstruction. This is a colleague of mine at Lenox Hill, Dr. Lerman who does a lot of autologous or implant based reconstruction. This was a nipple sparing mastectomy, and he did abdominal flap on both side. She has small breasts, but that's what she had at the beginning and she had enough abdominal tissue to do this. She had had a prior scar from a C-section down there.

This is again a nipple-sparing mastectomy and the patient had enough abdominal tissue. So she kind of got a tummy tuck at the same time again by Dr.Lerman.

And then this is a skin sparing mastectomy and her nipples were not spared, so her nipples were reconstructed. Those are reconstructed nipples and is the patient actually got a tattoo to cover up her abdominal scar.

So this is my patients, and is an implant based reconstruction. And this was a direct implant nipple-sparing reconstruction. So the patient woke up with the implants in place, in one surgery and done and the scars are hidden underneath the breast fold. So it almost looks like she had a breast augmentation. She pretty much kind of has the volume back that she had before.

Here is a prophylactic mastectomy and this is pre-pectoral. You can see that sometimes there's some more rippling in these cases but we can do fat grafting to help camouflage that. But this patient was so happy, having woken up with breasts that she just was done and really pleased and didn't want to do anything else.

So this was a difficult case. This is a patient who came to see me with a large breast tumor and she had had prior implants. Those are implants in place on the left and a prior breast lift. We were not able to spare her nipples. And this was her reconstruction. It's not perfect if you can see, but it gives you I think a realistic option of what can be done, and she's actually so much happier with her reconstructed breast that she was to begin with. And she had no interest in reconstructing her nipples or areolas at all. And I did do fat grafting to kind of help fill her out. She wanted to be bigger than she was before.

This is a case where the woman was pretty asymmetric to begin with. She had expanders put in and those were exchanged for four implants later on. She was very pleased. She wanted to be bigger than she was before and you can see she's pretty happy because she's been hanging out at the beach, which I always say is kind of a No-No in general for skin cancer, but you can see her tan marks, which is always a good sign.

Here's another one. This was a smoker. I almost delayed her reconstruction altogether, but we got away with it; nipple sparing the pectoral expander implant; so two surgeries.

So to sum it up, just a couple of things I wanted to make a point about. Sensation often does not return after mastectomy. That's something that's been in the news a lot over I think the past two years, and the New York Times has done a lot about that and it's due to the mastectomy and really it has nothing to do at all with your with your reconstruction. Something to keep in mind is that symmetry is most easily achieved on a bilateral procedures performed at the same time. So basically, both sides are done and I do kind of from a cosmetic perspective always bring that up, and I think it's a good question to ask and to discuss with the breast surgeon, because it does kind of give the plastic surgeon the most control at achieving symmetry. The bottom line is we've come a really really long way even from the time when I was a resident in terms of techniques and options and my goal is always to make you look and feel good in a bra and without one and I think that's really really important. I think that this is not I think once they once the cancer treatment is done. I think it is okay to really focus on wanting to look good and be really happy with the way you look. I've had patients come to me who had reconstructions in the past and you know, I think one of the things that we that we talked about is you don't you don't have to stop and just be satisfied. If you're not happy, I think that the we're always, you know, kind of moving forward or there are more advances being made and there are more options and I think it's okay to consider those. I think that it is important and very important that you want to and should feel good about the way you look, after your mastectomy and that you see a surgeon both a breast surgeon and a plastic surgeon who work as a team to achieve that goal for you. Thank you.

Bonnie Beckoff: Thank you. Dr. Preminger for taking the time to explain reconstruction options to all of us. That was amazing and super informative. Your expertise and knowledge on the topic of reconstruction and what to expect is extremely helpful. We truly appreciate all that you do on behalf

of Sharsheret. And now it is my pleasure to introduce our last speaker of the evening Debbie. Debbie is a Sharsheret peer supporter who has agreed to share her personal story of how body image and sexuality were impacted after her cancer journey.

IV. Personal Story

Debbie: Okay. Hi everyone. My name is Debbie and I'm a mother of three. Before I share my story, I'd like to thank the organizers for inviting me to talk and the panelists for sharing their insight and experiences with us. I think the topic of this webinar is an issue that is so important to so many of us but is often pushed aside for the more medical aspects of our situations. I want to thank all of you for logging in and for being here. We all have different stories and we are all at different points in our journey or the journey of somebody that we love, but many of us face similar challenges and it's always nice to know that we're not alone.

Shortly before Rosh Hashanah of this past year, I felt a lump in my left breast, right behind the nipple. At first, I thought I was imagining it. But the more I felt it the more obvious it became. My husband was away at the time and I didn't tell him because I didn't want to worry him. I knew that it was statistically unlikely that it was cancer, even though my mother had breast cancer a few years ago. She was postmenopausal and all of her genetic testing was actually negative. I was 44 years old. I scheduled an appointment for a mammogram and ultrasound and two days before Yom Kippur, I had I had to tell my husband that I had breast cancer.

I had my biopsy done the next day. Yes, erev Yom Kippur. Yom Kippur was pretty intense last year and I got the results a few days' later- invasive ductal carcinoma and DCIS in the left breast. Fortunately, the lymph nodes and the right breast looked normal. The MRI confirmed that the disease was limited to the left breast. But because of the extent of the DCIS, I would need to have a left mastectomy and because the tumor was right behind the nipple, obviously a nipple sparing procedure was out of the question. My genetic testing was entirely negative. So I was given the option of whether I wanted to remove just the left breast or take both of them. I had really small breasts. I mean, I wore a size 32A bra on a good day and over the years my friends and I talked kind of jokingly about getting an augmentation. I don't think I ever would have done it, but now I had the opportunity to get bigger breasts free of charge. Several of my friends referred to it as the silver lining of my having breast cancer. All of them including my doctor said just take both of them. It's easier for the reconstruction and that way you never have to worry about cancer on the other side, and you get fantastic boobs for free. It seemed like an easy answer but I'm a person who needs data. I Google everything and I'm a doctor. I'm a pediatrician not an oncologist or even an internist so I know just enough to get myself into trouble. I started researching breast cancer and reconstruction. I looked online and asked everyone I could think of from med school friends to Physicians I know now, to everybody in between who might know anything about it for their opinions and their

advice. I considered implants versus flat procedures and I looked into the pros and cons of each. You would not believe how many people I've talked with about breasts.

I think the doctor in me subconsciously approached it as a clinical issue more than a personal one which made it a lot easier to discuss it with the male Physicians I know socially. At some point during my investigation, I discovered that with a mastectomy, I would lose sensation to my breast. I actually really like the fact that Dr. Preminger mentioned it because, I am while I'm not sure where I found it out, I really don't think any of the doctors I met with mentioned it. It was either something I found online or something that way one of my surgeon friends mentioned. My own breast surgeon may have mentioned it, but she certainly didn't focus on it in any way. I met with three different plastic surgeons and none of them brought it up when I mentioned it. They said yeah, but you know, it might come back, but from my research and talking with other women as now well as my own experience, retrospectively getting back a significant amount of sensation after a mastectomy is incredibly rare, if ever. But all the plastic surgeons that I met with kind of shrugged it off like it was no big deal for me. Though for me, it was a really big deal. My breasts were incredibly sensitive and a really important part of my sex life. I know that isn't true for everyone but it really was for me. My breasts were easily my strongest erogenous zone. I like sex and I liked how it felt when my breasts were touched. It totally enhances sex for me. So once I realized I would lose sensation, I began to question whether doing a double mastectomy was really the right choice or if I should only remove the left after all my right breast was healthy; so there was no reason to think I had any higher chance of getting cancer there than anyone else did. I tried asking some of the people I know who've had double mastectomy, if how they felt about the loss of sensation. But I was uncomfortable asking about their sex life. So I was kind of stuck then with my questions and didn't really get any answers.

One woman I spoke to who is another Sharsheret peer supporter who had a double mastectomy, seemed surprised that I would worry about it. And she told me that none of the women she had counseled through Sharsheret had ever expressed concern about losing sensation. I had a hard time believing that no one felt that way. I did but I'm sure that even if they did feel similarly, they likely didn't feel comfortable talking about it. I mean, we don't really talk about things like sex particularly not with people we don't really know very well. In the end and after a lot of internal debate and discussion with my husband and doctors I did have a double mastectomy, but my reason for removing both breasts was more of a vanity issue than a medical one. It wasn't to eliminate the risk of breast cancer in the right breast, but because I needed to feel good about how I looked after all this was done. As I said, I started off with really small breasts and my right breast was actually the smaller of my two breasts which meant that if I wanted it to match the left after reconstruction, I would likely need to have an implant put on the right and while it was technically feasible to do that, and the risk of losing sensation obviously

much lower, but there's still a risk of losing some sensation with an implant. And more importantly, having an implant on the right would make it more difficult to detect any cancers that might develop there. So I decided that taking all of this into account, overall long-term I would be happier if I did the bilateral mastectomy. I decided on an implant versus a flap because of the relative risks and recovery of each and I decided on staged implants so that I would have some control over the size because I wanted to at least be happy with how I looked after all of that was done.

I had my initial surgery in October of 2018 and went through four rounds of chemotherapy along with adjustments to my breast size. And on May 2nd, I changed out the temporary implants for permanent silicone implants. At that time I had a nipple reconstruction done on the right and on the left. Actually the surgeon, Dr. Preminger, I figured I'd throw this out used part of my right nipple to reconstruct the left because I have very big nipples. I guess the breasts look okay, but I have no sensation on either side and it is really hard. I like sex, both the way it makes me feel closer to my husband emotionally and the physical act itself and I loved foreplay. Now it's just not the same as it was before. It's a lot harder to become aroused without having sensation to my breasts. They were my on switch, and now that switch is permanently off. On top of that, I'm on medications which affects my libido and with my scars, I don't feel sexy. So sex is really different now both for my body and for my brain. Thankfully I have an incredible husband who I can discuss all of this with and we are working together to find ways for me to enjoy sex as much as I used to but it is really hard and I really miss having sensation in my breasts. I think that the only reason I don't regret taking the right one was because after the mastectomy, they did a biopsy of some of the tissue and they found some atypical cells on the right. Nothing cancerous or even DCIS, but cells that were not normal, and one day may have evolved. Even with that some days I wonder if I should have left the right one in place.

I was at a seminar about two months after my initial surgery on the genetics of breast cancer in the Jewish population and a woman got up to speak. She had a BRCA mutation, as did her mother. She didn't get tested for it until after she developed cancer, unfortunately, and at the time of that seminar she had recurrent metastatic disease. She was trying to encourage women in the audience to get genetic testing. She said getting testing and having a mastectomy is no big deal. I sat there thinking, I'm not going to argue with you because our situations are very different, but it's not no big deal at least not to all of us. Yes, it's certainly better than the alternative, but it's not no big deal.

People keep asking me if I love my new breasts and they don't want to hear that I don't, even if they look better than my old breast did. They're not my breasts. They don't feel like my breasts and they don't behave like my breasts. So no, I don't love them there the consolation prize but nobody wants to hear that. So I just say something non-committal like I'm getting used to them and they're okay and still things like that. I mean after all I shouldn't complain I should be happy. I didn't die for my cancer. Right and I am happy that I didn't die. Don’t get me wrong; I’m incredibly

thankful that I found my cancer early and had an excellent prognosis. And I'm immensely glad that laws exist saying that insurance must pay for breast reconstruction, so that woman don't have to feel deformed on top of everything else. But it doesn't change the fact that there was a cost and there is loss here. And when I look in the mirror, I'm not yet happy with my body. I'm incredibly grateful that at least my husband understands how I'm feeling and supports me and I'm hoping that as I get further out from my surgery, and the scars fade, and my hair grows back from chemo; I start feeling more like myself and liking how I look a little bit more, but I don't know that I will ever love my new breasts. At best, I may be happy with how they look.

I'm sharing my story for several reasons. For one thing, unlike Dr. Preminger, not all doctors mention this quote “minor” side effect of mastectomy. Sadly, there are women who go in for surgery not realizing that when they wake up, they will no longer have sensation in their breasts and I don't think that's fair. I think that women should know the cost of the procedure beforehand. I know that some women won't care either. They don't have a choice medically or they don't have particularly sensitive breasts or even if they do it wouldn't change the plans, but for some it may change what they decide to do, and even if it doesn't they should be aware so that they can mentally prepare themselves as best as possible for this loss. For me and my extensive online searching, I know that I'm not the only one having had a mastectomy who feels this loss. But I also know that many especially in our communities don't feel comfortable talking about it, or they may feel guilty for even feeling it. I know that some days I do, but I'm okay with talking about it, and I wanted those women who feel the same to know that they aren't alone. Thank you.

Bonnie Beckoff: Thank you Debbie you for sharing your story and being so honest with our listeners. I am sure that a lot of what you said resonated with many of the people listening in today. We will now begin our question and answer period you can type your question in the text box located in the dashboard to the right of your screen. We already have a few questions come in. So we will begin with those your feedback is valuable to us because we are committed to staying relevant by enhancing our programs to reflect the growing and changing needs of women and families of our shared community with that in mind. You will be receiving an evaluation in your email box the next couple of days. Please take a few minutes to complete the survey.

V. Questions and Answers

Bonnie Beckoff: The first question goes out to Rachel, can you speak more about if a woman opts out of having reconstructive surgery and then finds it difficult to feel sexy afterwards and communicating this with her husband or partner?

Rachel Hercman: The question is just to clarify, opts out meaning….

Bonnie Beckoff: She opts out reconstructive surgery.

Rachel Hercman: Okay, so obviously it's a longer discussion because I have other questions like what was the before right? Like how the couple's communication was before cancer came into their lives. But what I will say is this there's your sexual dynamics as yourself and your sexual dynamic with your spouse. I find for some women they're able to process the experience of the change in their body; they're able to process that with their spouse. Okay for other women, it's helpful for them in therapy to kind of come to terms with it and develop a language and then be able to learn how to communicate it to their partner. I'm not sure if the question is Bonnie, like, how do you how do you navigate the conversation itself versus how do you get turned on like I'm not sure exactly what the specifics are of that, but I find that a really a lot of it depends on where the person is at in their own kind of ability to talk about it, where the couple is at and you know, I think it's been mentioned tonight several times that idea of rolling with those punches of as a couple can we grieve together sometimes about what this has done to our relationship or how things have changed in an unexpected way. I do find that for some couples the partner is still very attracted to them but the woman herself feels disgusting, but then it's kind of like I don't want to be part of a club that would have me as a member right? So sometimes you know, their spouse is still attracted but the woman herself feels disgusting or sometimes the woman feels good, but the spouse is still dealing with the changes. So I think there's different dynamics there that can all affect things.

Bonnie Beckoff: Thank you so much. We really appreciate that response. The next question comes in is for a Dr. Preminger. If a person initially decides not to have reconstruction and opts out and then wants to have reconstruction at a later date, is this a possibility?

Dr. Preminger: Absolutely. I am I'm actually happy somebody asked that question. It's always a possibility. You have not burned any bridges at all by not opting to do the reconstruction initially. So the options are completely still available. The only thing is, I would mention is that with an implant based reconstruction, you really do have to, usually do the expansion again first, because that skin has really scarred down to the chest and we need to be able to make space to put an implant in again. I see women come back after 20 years and suddenly decide- you know what I'm going to do this.

VI. Conclusion

Bonnie Beckoff: thank you so much and in the interest of time, thank you to everyone who handed in and who wrote in questions. I know the time is getting late, but I just wanted to remind everyone and I know I said it before but you will be getting an evaluation in your email box the next couple of days. Please take a few minutes to complete the survey. What you say greatly enhances our programs and the changing needs of our women and our families that we help every single day in the Sharsheret community. A video transcript from tonight's presentation will be available on

Sharsheret's website, and you can access it by going to the link that's on your screens. I would once again like to thank the Seigmund and Edith Blumenthal Memorial Fund and Sientra for sponsoring tonight's program and their continued support of Sharsheret. The conversation doesn't have to stop here. You can visit Sharsheret at its website at www.sharsheret.org or call us at 866-474-2774 to discuss tonight's topic or any other concerns you are facing. Thank you so much for joining us. Thank you Rachel Hercman and Dr. Preminger and have a great rest of your night.

VII. Speakers' Biographies

Rachel Hercman, LCSW, earned her MSW from Wurzweiler School of Social Work and has a clinical focus on relationship and health, self-esteem and trauma. Her background in mental health and medical settings help inform her appreciation for the mind-body connection in our functioning. Rachel currently has a private practice in Manhattan and enjoys working with a diverse clientele.

Dr. Aviva Preminger, MD, MPH, FACS, is an Ivy League educated, Board Certified female plastic surgeon specializing in cosmetic and reconstructive surgery of the face, breast, and body. She holds faculty appointments at Columbia University as well as several other fully accredited New York hospitals. Dr. Preminger trained at some of the country's finest institutions including New York Presbyterian-Weill Cornell Medical Center, Columbia University, Memorial Sloan Kettering Cancer Center, Manhattan Eye and Ear Infirmary, Lenox Hill Hospital, and the Hospital for Special Surgery. She also studied art at the Art Students League. In addition to achieving top honors in some of the most distinguished Ivy League schools in the country, Dr. Preminger has a history of active leadership in many professional organizations and holds a position on the medical board of advisors for Sharsheret. Dr. Preminger has expertise in a wide range of cosmetic and reconstructive procedures and has lectured and published extensively.

VIII. 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

IX. Disclaimer

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care Professional. The document does not recommend the self-management of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

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