

Prophylactic Surgery For Breast and Ovarian Cancer: How Will It Affect Me?

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I. Introduction

Shera Dubitsky, MEd, MA, Clinical Supervisor, Sharsheret

Shera Dubitsky: Thank you, and good evening everyone. My name is Shera Dubitsky and I am the Clinical Supervisor at Sharsheret. I'd like to welcome all of you to Sharsheret's National Teleconference, Prophylactic Surgery for Breast and Ovarian Cancer: How Will It Affect Me?

Sharsheret, which is Hebrew for chain, connects young Jewish women and families to our community of support in the way that feels most comfortable, taking into consideration their stage of life, diagnosis or treatment, as well as their connection to Judaism.

Joining us this evening we have women touched by breast or ovarian cancer, women at high risk of developing cancer, medical professionals and a wonderful panel of speakers representing many states across the country including Virginia, New York, Chicago, New Jersey, Florida, Milwaukee and Atlanta.

A woman diagnosed with stage II breast cancer, called Sharsheret last year to get more information about genetic testing. She shared a conversation that she had had with her doctor. The surgeon told her that he didn't want to schedule a date for surgery until this woman went for genetic testing. She said, "why would I need genetic testing?" He said, "the results of your test could influence your decision about prophylactic surgery for the other breast and because of your ethnicity I want you to get tested."

This woman responded, "what does my ethnicity have to do with anything?" He explained to her that Ashkenazi Jews are more at risk of carrying the BRCA mutation. She paused and asked, "well, what if I convert?" The doctor said, "that won't help and besides I don't think your rabbi will be too pleased with that suggestion."

As many of you already know, genetics is a very real concern in the Jewish community. One in 345 individuals in the general population carry the BRCA mutation. For Jews of Ashkenazi descent, that number is one in 40. Having a family history of breast or ovarian cancer has often been described as living with a ticking

time bomb. There are psychological, psychosocial and physical implications of knowing your history and undergoing genetic testing. We have addressed the issue of genetics in several past symposia and I encourage you to access the transcripts and audio recordings from the Sharsheret website at www.sharsheret.org. We also have a licensed genetic counselor on staff and I encourage you to call the Sharsheret office to speak with her if you have any specific questions or concerns.

Some women have called Sharsheret concerned about making the decision to undergo prophylactic surgery in the context of Jewish law. I have yet to speak with a woman whose rabbi did not support her decision to have the surgery. Most spiritual leaders, in fact, understand that for the protection of one's health — which is a strong Jewish imperative — this surgery is acceptable in the context of Jewish law.

Deciding to undergo prophylactic surgery is very personal. Women approach this decision at various stages of life experiences taking into account the many variables that she is faced with. We at Sharsheret have seen a significant difference in how women are approaching this decision based on their family history or their own experience with cancer.

I spoke with a woman this week who was approached by a cousin of hers who tested positive for the BRCA mutation. Her cousin encouraged her to get tested for the gene. Initially, she dismissed her cousin as being overly reactive. After all, how can you remove currently healthy parts of your body, she thought to herself? This woman didn't know of any immediate family member with cancer and she saw no reason to go for testing.

The cousin, however, pressed her and she finally agreed to test for the BRCA mutation. After falling off her chair when she found out that she was BRCA positive, she initially opted for increased surveillance. After several discussions with her doctors she decided to undergo prophylactic surgery and never looked back. When I asked her what her hesitations were prior to making the decision to have surgery she said, "I didn't know these relatives with cancer, so it just didn't seem relevant to me and I didn't consider the implications of the increased risk."

For women who have been diagnosed with cancer or who have watched somebody they love undergo treatment for cancer or, sadly, die from cancer, the hesitations to

undergo prophylactic surgery are often brief if they exist at all. Women diagnosed with breast or ovarian cancer have already contemplated their own mortality. For these women, prophylactic surgery is often seen as the next step in the treatment to reducing their risk of another cancer diagnosis.

Many women who do not have a cancer diagnosis, but are at an increased risk of developing breast or ovarian cancer, see themselves as patients in waiting. These feelings have propelled them to forego the ongoing screenings because the anxiety is too overwhelming each time they go for mammograms, MRIs or sonograms. Contemplating prophylactic surgery can feel frightening. What will I look like? Will I feel the same way about myself? How will my partner experience me?

For other women, the option to undergo prophylactic surgery is empowering. This is an option that their loved ones perhaps didn't have. Being able to be ahead of the cancer enables women to feel like they have a degree of control over their health and well being.

I suspect that women who do not know an immediate family member diagnosed with cancer will take more time in decision making whereas those women diagnosed with cancer or who have witnessed a loved one struggle with cancer are more likely to act immediately. The impact of this is critical because it influences how a woman approaches her options. Is she taking the time to meet with several doctors and plastic surgeons to get information? Is she taking the time to learn about the various surgical and reconstruction options, oophorectomy versus hysterectomy, tram flap versus implants. Is she working with her insurance company to cover the surgeries, taking the time to appeal claims that are not in her favor?

I suspect that women feel a range of emotions from frightening to empowering, feeling overwhelmed to breathing a sigh of relief. Tonight our goal is to address some of the concerns women may have once they have determined that they can benefit from the surgery. Our panel of speakers will discuss the physical and psychological implications of prophylactic surgery, and share personal stories. We will have a question and answer session following the presentation.

I would like to introduce Dina Roth Port. Dina is a freelance writer, journalist and author. Her book for women at high risk for breast cancer, titled *Previvors: Facing*

the Breast Cancer Gene and Making Life-Changing Decisions is one of the most thorough resources out there addressing this issue. Dina's writing has also appeared in many magazines such as *Glamour*, *Self*, *Parenting*, *Cosmopolitan*, *Natural Health*, *Fitness*, *Martha Stuart Weddings* and *Prevention*.

A graduate of Northwestern University Medill School of Journalism, Dina first worked as a health editor at *Glamour* magazine. There she wrote and researched pieces on breast cancer. It is now my privilege to hand the proverbial floor over to you, Dina.

II. Guide for Previvors: Inspiring Stories and Helpful Hints

Dina Roth Port, Author, "Previvors: Facing the Breast Cancer Gene and Making Life-Changing Decisions"

Dina Roth Port: Thank you, Shera. Thank you to Sharsheret for having me as a part of this important teleconference. I thought I'd first explain why I wrote my book *Previvors* and how it came about.

About three years ago, I was working for different national magazines writing primarily health articles and I was approached by five women who were living in my community. They were five women I had never met before. They told me that they were previvors —w hich at that point was a word I had never heard. They explained that a previvor is a person who has not had cancer but has a predisposition to develop it.

At the time, they had all already taken steps to defy their fate. But they told me that when they were going through weighing their options and determining their risk, they had each other to rely on but they didn't have a resource to turn to, one guidebook that could really help them. At that point there weren't even any memoirs out. This was about three years ago and there really was nothing out there. They said there were plenty of books for breast cancer survivors and breast cancer patients but none for women like them. They asked me to write a book for previvors.

I got home and started to do some research about this whole new way of looking at breast cancer and as a writer I was shocked. There are thousands upon thousands of women out there who are living with a high risk of breast cancer. They have watched family members suffer and they're scared that they're going to be next in line in their family and they really didn't have a resource to turn to.

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As a woman, I was angry because I know far too many people who have battled breast cancer and found out that they were at high risk after it was too late. They should have known that they were at risk and they should have known what their options were to protect themselves. But, ultimately, they were diagnosed with breast cancer and couldn't take those steps to protect themselves.

I decided that I would tell the stories of these five women. Their names are Lisa, Mayde, Amy, Rori and Suzanne. I also included research based on interviews with more than 70 leading medical experts to really create a true comprehensive guide for previvors.

As Shera pointed out, it's important to talk about these issues in the Jewish community because Ashkenazi Jews have one in 40 odds of having a BRCA mutation. That's why it's so important to look at both sides of your family, know your family history on your mother's side and your father's side. If there's any question if you're at risk, you need to talk to a genetics expert to find out whether or not you should get tested for a BRCA mutation, whether or not you might want to consider having a prophylactic surgery and other issues that might arise because there are a lot of psychological, emotional and physical issues that you might face.

Tonight, we're going to talk about prophylactic surgery but I want to emphasize that that is just one option for previvors. You could do increased surveillance, by doing mammograms more often and earlier. It is suggested that average women start at 40 years old, but you might want to start that earlier and more often adding MRI to the regimen and ultrasounds. There are drugs you can take like tamoxifen and raloxifene which can lower your breast cancer risk up to 50 percent. There are lifestyle changes and for ovarian cancer, you can take oral contraception and that can lower your risk.

In general, the decision to, ultimately, have prophylactic surgery is not a decision that people make lightly. People reach that decision for all different reasons. Of the five women in my book, three of them had a BRCA mutation but two of them did not. They all had very different stories but, ultimately, had the same outcome.

For instance, Suzanne's mother died on her first day of kindergarten. Suzanne was four years old at the time and grew up in utter fear of breast cancer. She would have

her mammogram every year and then bury her head in the sand until her following mammogram and never really did much about her risk besides that.

She then had a daughter and Suzanne realized what it was she had missed out on. She realized that growing up, when she was in dance recitals and her dance teacher would do her hair, all the other little girls had their mothers fussing over them doing their hair and doing their makeup. When Suzanne got married, there was nobody there to help her pick out her wedding dress. When she had her daughter, no one taught her how to swaddle a baby and Suzanne said; “there’s no way I’m going to let my daughter grow up the way that I did.” She, ultimately, decided to have a prophylactic mastectomy.

Amy, another girl in the book, always thought that she would someday grow up, go to college, get married, have kids and get breast cancer. It was just a way of life in her family. Her grandmother died of the disease before she was born. Her mother and her aunts are both survivors. For her it was a question of when, not if, and ultimately when she tested positive for a BRCA mutation she felt like she had no choice but to have the surgery. She felt it was inevitable that she was going to get breast cancer.

Once you decide to have the surgery, it can be very frightening, confusing and scary. But there are ways you can make sure that you’re choosing the right surgery for you and the right doctor. By doing this as a preventative surgery you have the luxury of time. You’re not rushed into finding your doctors like a woman diagnosed with cancer might be. You can do research until you’re comfortable with the surgery and your doctors. You can explore your options and there are other options. I do want to emphasize that, again. This one is right for some people, but not for others. It’s a very personal decision and that’s why it’s crucial to do all this research.

Luckily, today you can achieve cosmetic results that look completely natural. The surgical option has improved greatly over the years. To start with, in the past they used to do radical mastectomies where they would remove basically everything on the chest wall, lymph nodes, chest muscles, everything.

Today many women have what’s known as a total mastectomy which is removing the breast, nipple and areola. There’s also a skin-sparing mastectomy which preserves

the skin of the breast and only the nipple and areola are removed. A nipple-sparing mastectomy preserves the skin of the nipple as well.

This has been somewhat controversial. Some people feel like if you're going to have a prophylactic mastectomy you might as well remove everything but other people feel like the slight increase of risk you might have from having a nipple-sparing mastectomy is worth it for the cosmetic outcome. Your risk is still way below that of the average woman and the outside of the breast remains completely intact. It's just what's on the inside that changes. So this is a very personal decision and something you should definitely talk to your doctors about.

Some women choose not to have reconstruction, but, for those who do, you have the choice of whether to have a flap surgery or implants. Implants are pretty straightforward. A flap surgery is when they take tissue from another part of your body, whether it be your stomach, your back or buttocks, and recreate the breast with that tissue.

There are pros and cons of having a flap surgery versus implants. For instance, flap surgery is a longer surgery. It requires incisions at both the breast and the area where you're taking the tissue. But one of the pros is that it doesn't require a foreign substance to be placed in your body. The flap tissue is fully integrated in your body, so it tends to look more natural than implants. If you gain or lose weight, your breasts will too—where implants remain the same size over time.

The benefit of implants is that it's a shorter surgery. There are only incisions on one part of your body and your breasts don't sag over time. However, the implants can leak or rupture and the implants are not considered lifetime devices. Many will have to be replaced at some point so there are different things to think about when you're considering the surgery.

Saline and silicon implants are both available today. Most experts prefer silicon implants over the water balloon-like effect of saline. But, again, it's a personal choice. Also, when you're considering prophylactic surgery, mastectomy, there are also expanders versus doing what's relatively new, these one-stage surgeries.

The traditional way of doing implants is that a silicon shell balloon goes under the skin and muscle right after the mastectomy. Over months, a doctor or nurse will

inject the expander with saline through a valve in the device that stretches the skin and chest wall to create a pocket for the implant and then in a separate surgery the expanders are replaced with permanent implants.

One-stage surgery removes the need for expanders. Some surgeons use what's called an acellular skin graft to extend the muscle and create a pocket for the implants. This gives the implant more padding to hold it in place.

This happens to be the technique that the women who I feature in my book all chose. That was the bond that brought them together. It was a pretty cutting-edge surgery. It's commonly referred to as Alloderm One-Step, but there are other materials that are used now.

There are also other options. But they wanted the nipple-sparing mastectomy, which is what this is, for the cosmetic outcome and they liked the idea of the one-stage surgery because for them they just wanted to get it over with. They just wanted one surgery. I mean, there can be revisions but the initial surgery was just done in one swoop with the mastectomy and the reconstruction all at once.

Once you choose the kind of surgery that you want to have, it's time to find a doctor. Ideally, you would look for a multi-disciplinary center where doctors are used to working together where you have genetic counselors, psychologists, breast surgeons and plastic surgeons, all in one place. That's an ideal situation. Obviously, it's not possible for everybody but if you can that's the way to go.

You can go to different organizations like the National Cancer Institute and the Association of Community Cancer Centers, they're all great resources. I have contact information for all of them on my website at Previvors.com. Also, on Previvors.com, I list resources to find breast surgeons, plastic surgeons and other doctors you might need.

It's important to make sure that the doctors you look for are board certified. You also want to make sure that if you're going to a doctor, for a particular kind of flap surgery, that that doctor primarily does those kind of flap surgeries and isn't doing mostly implants the rest of the year or different kinds of flap surgeries. You want to make sure they have an expertise in that area.

The most important thing is that you feel comfortable and that you just keep looking until you find that doctor you feel comfortable with. I mean, that's pretty much the most important aspect. You want a reputable doctor, but in some ways the most important key is that you feel comfortable with your doctor.

In my book, *Previvors*, I have a list of questions you might want to ask the different surgeons for the different surgeries. Questions like: how many surgeries have you performed each year? Can I see before and after pictures? You could ask them, specifically, about what costs you should expect to incur and how you're going to look and feel after the surgery.

It's also key to be prepared for the surgery. In the book I offer checklists of what to bring to the hospital and what to prepare ahead of time. They're pretty extensive lists but I'll give you an idea of what to bring to the hospital for different surgeries. After a surgery, you'll need button-down or zip up shirts, sweaters or sweatshirts because you won't be able to put anything over your head. You should also remember to bring copies of your medical records, your insurance card. You may want to bring sleeping aids at the hospital and sucking candy to help you with the sore throat from having a breathing tube inserted during surgery.

In terms of what to prepare at home ahead of time, good tips that I include are that you should try to book the first surgery of the day because there tends to be more delays as the day goes on. Also, put all of your dishes, glasses, clothing anything you might need at counter level so you won't have to reach for them after the surgery. Fill any prescriptions you might need ahead of time for pain medications and things like that. There are many more tips like that in the book.

A lot of women want to know what to expect after the surgery and, of course, it's very different for each woman, depending on her surgery, her doctor her body and how it heals. To give you an idea of what to expect after a mastectomy, there are drains to drain excess fluid that comes out of the incision site. There are little plastic tubes that go from the wounds into these little collapsible containers and you or a friend or family member will have to empty the containers as many as six times a day for up to two weeks.

Most women say the drains are the worst part of the surgery. A lot of the women I spoke with in my book and even other women complain about the drains. Amy, from my book, says that they were so painful and uncomfortable and she was so sick of the drains and it made a huge difference once they were removed. They are temporary but they're no fun, so it's one of the worst parts of the surgery, a lot of people say.

There will be bandages over the incisions after the surgery. Usually a mastectomy incision is closed with dissolvable stitches. They might feel like little bumps under your skin. If your doctor uses surgical staples he'll remove them at his office during your first visit, after your operation. There will be some bruising which will vary greatly per person. Amy said her breasts turned black and blue, then purple, then yellow and, again, the bruising will fade within a few weeks. Scarring varies greatly. Some women have small, light scars hidden in the breast folds. Others have larger, more conspicuous ones that can appear very dark pink or purple. It really depends on your surgeon, your breast size and how you tend to scar. There are some suggestions on how to help the scars appear lighter and smoother which I detail in my book.

Also, a lot of people complain about just feeling exhausted after the surgery, just like any surgery, really. Usually it takes about one or two months before you start feeling less tired. It decreases over time, though I know that one of the women in my book went to see a Broadway show within a week after having the surgery and bounced right back. Suzanne, who's a dance teacher, was back teaching within two weeks. So it really varies per person.

Of course, there will be some pain which can be helped with different kinds of pain medication, so don't be afraid to ask your doctor for pain meds. One of the girls from the book, Lisa, says it felt like she had an elephant sitting on top of her chest and two rocks where her breasts once were. She had implants so that also varies.

A lot of women want to know about numbness. Most women will have numbness in their breasts at first. One doctor estimated that about 60 percent will regain some feeling over time. Some patients wind up with total numbness while others have full feeling. Nerves grow slowly so it can take years to get considerable feeling back.

If a woman has a high risk for breast cancer because she has a BRCA mutation, then she's likely considering whether or not to have her ovaries removed as well. It's known as a prophylactic oophorectomy. One of the women in my book chose to do that. Her name is Rori and she lost her mother to the disease and her sister battled it, so she did feel like her ovaries were a ticking time bomb.

There are other options to battle ovarian cancer. Birth control pills decrease ovarian cancer risk by 50 percent. However, oral contraception can also increase your risk for breast cancer so you need to talk to your doctor about what's right for you.

The screening methods are notoriously bad for ovarian cancer and it's known as the silent killer. People often tend to consider having their ovaries removed because it's very hard to detect ovarian cancer early. An oophorectomy reduces odds of breast cancer by 50 percent and ovarian cancer by 80 percent. Doctors usually remove the fallopian tubes, as well, and the whole surgery together is called bilateral salpingo-oophorectomy. There is some residual risk because cancer might start in the peritoneal lining.

In terms of where to find a doctor to perform these surgeries, you should go to a gynecological oncologist. You can go to the Society of Gynecologic Oncologists, or, if you go with a gynecologist, then there is the American College of Obstetricians and Gynecologists. Again, all of this contact information is in the book, as well as on Previvors.com.

Laparotomy is the traditional way the surgery is performed. A doctor makes up to a six inch incision and surgically removes the ovaries and fallopian tubes. The laparoscopy is done under anesthesia. The surgeon makes an incision in the belly button through which he or she inserts a small camera called a laparoscope. This device lets them see the ovaries and other organs up close. Then the doctor will make a few incisions around the pubic area or lower stomach through which he or she surgically removes the ovaries and tubes.

Some women also consider whether or not to have a hysterectomy and remove their uterus. If you keep it then you're still at risk for uterine cancer and a small bit of fallopian tubes can still be attached to the uterus so, theoretically, that could also develop into cancer. But a hysterectomy might lead to diminished sexual function

and bladder problems, so it's important to weigh the pros and cons with the help of your doctor.

Removing your ovaries will put you into surgical menopause and also lead to infertility. Suzanne and Amy in my book, both tested positive for BRCA mutation and neither of them has had the surgery yet. They're afraid of going through premature menopause. Rori had the surgery right away because she saw far too many relatives battle ovarian cancer, but Suzanne and Amy have yet to have that surgery.

The women in my book all already had children but this is a big issue for a lot of women which I do address. Especially for the young single woman who is contemplating her future, there's a big question of when to do the surgery. Doctors recommend that women have the surgery as soon as they are done having children or by age 35 or 40 but, again, it's a very personal decision.

That's pretty much the physical side of prophylactic mastectomy. I do address the emotional and psychological aspects of these surgeries, as well. It's a huge part of the book. I know Shera will be talking about all of this after me, so I'll just say that it's very important to find a support network. Sharsheret, FORCE and Be Bright Pink are organizations out there that could help you.

It is important to know that you're not alone. These five women asked me to write this book for them because they wanted to tell other women out there that you're not alone. You might feel that way, but there are plenty of people out there that can help you.

Also, on the website, women have been sharing their stories. There's probably a lot of you out there who are listening and could find someone to relate to. That's our hope, to help you feel less alone and to let you know that other people have experienced this.

There are a lot of emotional issues which we'll talk about later. Ultimately, all the women in my book had prophylactic mastectomies and Lori had her ovaries removed and they all say that while their decision wasn't easy they are all happy with their results. They no longer live with the fear of breast cancer that was consuming them. Prophylactic mastectomy is not an ideal option for anyone and, hopefully, it will

someday be a thing of the past but for now it is a viable option that dramatically lowers a woman's risk for breast cancer.

I also want to just stress that the overall message of the book, the whole concept of the word previvors is one of hope. It's a message of choosing strength over fear. One of the experts I talked to recently told me cancer is still smarter than us, but in some ways that's not true anymore. I think many previvors, like the ones in my book, are proving that statement wrong. They've refused to be outwitted by a disease that they've seen win far too many battles. Their mothers didn't have this great gift of knowledge or so many means to defy their fate. But we do. We can fight this illness before it strikes by learning our risk and the options we have to protect ourselves.

Please take the information you learn tonight and use it for yourself or a loved one. Remember that one in 40 Ashkenazi Jews have a BRCA mutation. So it's important that you learn this information for yourself, your children or other loved ones. It should give you control over a disease that has been winning for way too long.

I want to thank Sharsheret for initiating this dialog about this important topic. I encourage all of you listening who know that you're a previvor, please talk to an expert and at least learn your options. If not, I'm sure you know someone who is. So please help your friend, your family member or other loved one. Learn what they can do to protect themselves and, again, remember you are not alone. Thank you.

Shera Dubitsky: Dina, thank you for such a hopeful message and thank you for sharing your knowledge and insights on this topic.

Dina Roth Port: Thank you.

III. Psychosocial and Physical Side Effects of Prophylactic Surgery

Shera Dubitsky, MEd, MA, Clinical Supervisor, Sharsheret

Shera Dubitsky: I encourage all of you to read her book to continue to benefit from Dina's research and to get a more thorough discussion on this topic. As Dina said, I will now be discussing the psychological and psychosocial implications of prophylactic surgery.

Women have struggled with how much to share about their decision to have surgery or whether to share at all. Cancer has often been a taboo subject in the Jewish

community. Some women have decided to remain private about prophylactic surgery because they are concerned about what the implications of having a family history or a BRCA diagnosis will have on their family, particularly their unmarried children.

Other women have opted to remain private because they simply don't want to be judged for undergoing surgery that removes currently healthy parts of their bodies. It is difficult for some people to understand why anyone would opt for the surgery. Women feel protective and don't want to put themselves in a position to be judged. Some women opt to only share the information with people who are close to them.

For single women, sharing this information is a very difficult decision. They may feel uncomfortable sharing with their peers because their friends may not understand how they have come to this decision. They also worry that their friends will not be able to relate to the implications this has on dating. A single woman may not trust the information being out there where there are potential suitors who can find out about the surgery and, therefore, opt not date her.

Once a single woman is in a relationship how she shares the information is delicate.

I went to a conference a couple of years ago where I had heard that for a third of the suitors the information can really be a deal-breaker. For another third, it just doesn't matter and for the last third it depends on the nature of the relationship and how he feels about the woman. She needs to find the right time in the relationship to share this information.

It's important to recognize that married women set the tone for how the family will handle this decision. Open communication with her husband allows a woman to lay out what her emotional and physical needs will be. This is certainly not a time to expect ones partner to mind read. Open communication also offers the husband an opportunity to express his concerns and that also decreases the likelihood that they both have to manage this in isolation. Having the husband come to the doctor appointments may help him develop a better understanding of what to expect pre- and post-surgery.

Sharing information with children depends on the age and gender of the child. If a woman decides to speak with her children about the surgery it's important to convey the following messages. This is a responsible decision that will help protect mom's

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health in the future. She's modeling for her children the importance of being responsible for their own health, including proper nutrition and exercise. Mom's conveying that her decision comes from a place of empowerment rather than fear. She's teaching them the importance of being proactive in life when the opportunity arises rather than reactive. She's teaching them the importance of gratefulness and feeling thankful that we now live in a time of information and knowledge that offers these kind of options. It's important to speak with children in a way that is age appropriate. Women should therefore try to simplify the information when possible.

At the end of the day, whatever a woman decides to share with her children, it's important to be truthful. Women should also try to assess what children are really asking before answering any questions. Let the kids know what to expect when mom is at the hospital and after returning home from the hospital. Finally, like Dina was saying, it's important to send a hopeful message because, again, mom needs to remember that she's setting the tone for the family.

Women undoubtedly have a shift in their self-image post-surgery. For women who undergo prophylactic mastectomies there may be a sense of loss on several levels. They have lost part of their bodies that have been familiar to them. There are scars from surgery that are a permanent reminder of the measures that she needed to take to protect her future. We have seen that scars can mean different things to different women.

Young women who are hoping to expand their families feel a sense of loss in no longer having the option to breastfeed. Due to the loss of sensation in the reconstructed breast some women feel deprived of sexual stimulation that has been important during intimate times with their partners. Immediately post-surgery some women feel unattractive and perhaps unfeminine. Certainly, reconstruction today has lessened the cosmetic impact due to the various options that are now available to women to help them feel more attractive and more whole.

Other women love their new bodies. I had one woman share that she now has two perky breasts and a tummy tuck all for the co-pay of five dollars. There are women all across the country who have a new comfort level in showing off their reconstructed breasts to anyone that is interested.

These are examples of how some women have been able to embrace surgery and reconstruction, while softening their feelings of loss or change. I have found that women diagnosed with breast cancer experience less ambivalence about prophylactic surgery. Many have shared that they're just relieved to remove the cancer and lower the risk of future cancer at any cost. This does not dampen their feelings about the loss of their breast yet it somehow becomes secondary to their overall health.

For women who undergo prophylactic oophorectomies or hysterectomies, there's also a shift in their self-perception and change in their body image. As we know the natural course of development for most women is that it can take years of perimenopausal symptoms before entering complete menopause. The symptoms are gradual. Premenopausal women who have their ovaries removed or undergo a full hysterectomy are hit with symptoms of menopause almost immediately and dramatically. A young woman may feel a loss of youth. Her peers aren't experiencing hot flashes. Her peers are still getting their periods. Her peers are still having kids and she may feel like her new peer group are women in her mother's generation.

For women who are planning on growing a family, the loss of being able to procreate naturally is tremendous and profound. Raising families is a strong Jewish value. Removing the ability to procreate naturally can feel very painful to a young Jewish woman who is surrounded by peers who are continuing to grow their families.

As Dina was saying, women may feel more fatigue and, therefore, less productive than they are accustomed to following surgery, though, for most women this is temporary. Some women report increased mood changes and have less control over their emotions. They now worry that they're being perceived as erratic or unreasonable by others.

Women may feel less sexual interest due to their decrease in libido. Some women fear that the decrease in libido will make them less connected with their partners which can greatly impact the relationship. Some women have also experienced increased weight gain post-oophorectomy or hysterectomy for which women can also take an emotional hit. We live in a society where even women with "perfect bodies" can have poor self-esteem about their bodies. Weight gain after surgery only

heightens this concern. Women also worry that this may make them less attractive to their partners.

It's difficult to parcel out how much a relationship with a woman's partner changes because of his altered perceptions of her or her own fears of how she is being perceived. Some women worry that prophylactic surgery can negatively impact intimacy with their partner and these women may be feeling insecure. He may be experiencing his own concerns. She becomes hypervigilant to his gestures and may be ascribing meaning to them that don't accurately reflect how he is feeling. He may be acting more cautious as to not behave in any way that can be misinterpreted.

It's interesting. I recently spoke with a woman who suggested that because her husband had watched his mother-in-law die from ovarian cancer, he was very grateful that prophylactic surgery was an option for his wife, even though their sex life took a hit. She speculated that perhaps if he hadn't lived through the experience there would be more tension in the relationship around engaging intimately.

I wanted to briefly touch on identity issues that can arise. I had women who are at high risk of developing breast or ovarian cancer, ask, "who am I? I don't have cancer, yet, I underwent extensive radical surgery. I have scars. I'm identified as a previvor but I feel like I've experienced loss and recovery. My body has changed. My perception of myself has changed. I have moved on in my life. I am strong. Am I not, too, a survivor?"

I encourage each woman to define this for herself. In the end my experience, as Dina said, is that women have felt proud and empowered by their decision to have prophylactic surgery. The process may have been difficult and challenging but once on the flip side of the surgery most women, ultimately, feel a sense of ease and peace with their decision. Perhaps feelings of sadness may arise that women they know or women they loved didn't have this option, but these women feel hopeful that the next generation will have even more options available to them.

What are the takeaways? Research, communication and trusting the process. Doing thorough research and gathering information is key. Finding the right medical team is critical in how you will make and manage these decisions. Remember that you will set the tone for your family and loved ones. Open and honest communication with

the people you are choosing to share this with can optimize the likelihood that your needs will be met. Understand that this is a process. You may experience complex and sometimes conflicting emotions. It's important to allow yourself to experience the range of emotion, understanding that at some point you will feel more settled with your decision.

As Dina said, you don't have to be alone with this. We encourage you to continue to use Sharsheret as a resource. We can find you free and confidential peer support, a link who shares your experience, as well as your values and culture. We encourage you and your family to speak with our genetic counselor who can answer questions and address any concerns that you may have about hereditary breast or ovarian cancer.

Some of the topics discussed today have been explored in greater depth in prior teleconferences such as genetics, sexuality and intimacy, speaking with children, fertility, hormones. I encourage you to download these transcripts and audio at www.sharsheret.org for further information and discussion.

Women, family members, healthcare providers, community members and clergy can contact the Sharsheret office for resources and to find out how to bring Sharsheret to your community.

It is now my pleasure to introduce Alicia Altmueller. Alicia called us from North Carolina four years ago seeking support. She has since volunteered for Sharsheret by serving as a peer supporter several times over. Her story has been printed in Sharsheret's materials, and I have repeated her words of wisdom to many women calling Sharsheret for support and a compassionate experience. We're very grateful to have Alicia with us tonight. Alicia, the floor is yours.

IV. Sharsheret Callers Share Their Personal Experiences

Alicia Altmueller and Diane Harkavy, Sharsheret Volunteers and Peer Supporters

Alicia Altmueller: Thanks. I'm going to jump right in and tell you where I was at the time I found out I was a BRCA1 carrier. We had just moved from New York City, full of lots of Jewish friends, to a place where there were very few Jews. I had one 4-year-old and a 14-month old and I was just about to start looking for work after taking a year off.

Then my dad got a call from a cousin who called him to suggest he get tested. On mother's side of the family, there was no cancer except for my mother, she was not a BRCA carrier. On my father's side, it was all men and so it didn't even hit my mind that I would possibly be a carrier. My father tested positive. But even before I found out, my personality led me to set up all my appointments. I figured I could always cancel them if it turned out I was not positive.

While I waited for the results I educated myself, I researched, I called every medical connection I had locally and nationally. I met with the head of genetics at our local research hospital and asked him: "what would you recommend to your wife, your daughter, your sister or your mother?" I also talked with as many women as I could find who had the surgeries or were genetic carriers. Some conversations, I need to warn you, are better than others. Some of the conversations just don't connect but some of them really made major differences in my life.

When I found out that I was a carrier, it was my husband who suggested I call Sharsheret. He'd remembered it from a friend from New York who was a relative to the founder and he encouraged me to call. It was actually that call, that link that helped me make many decisions. Once I made my decisions it was as if a weight had been lifted off my shoulders and what I can say that the decisions I made were best for me because of my personality.

For example, I must have checked my breasts at least ten times a day, once I found out I was a carrier, every minute I had until the day I made my scheduled mastectomy. Now, again this was the right time in my life and the right for my person and for my personality. Everybody's different.

I met with my doctors at the end of November and I actually went with my ob/gyn—I'm sorry, my oncology gyn and he was ready to schedule the surgery immediately. I had had two daughters. We were not having any more children and I was still under 40 and I still am for another three months, and he wanted to do this before anything. That was his recommendation to me because of my history.

I took a vacation before I did it because there were no signs. And in January 2007, I had a total hysterectomy which included my uterus. That was a laparoscopic robotic

surgery. I joke around that my surgeon, my oncology gyn actually never touched my body. It was purely robotic.

Then following in March 2007, I had a total bilateral mastectomy with expanders. I was one of the folks that actually had to go through the expansion process and then have another surgery for the silicon implants. I also continued through the whole process and I have, through my scar tissue, created nipples and I also have done the tattooing. From start to finish, I finished the process in the summer of 2008.

How did I do it? I did it with the love and support of family and friends. Everyone has to decide on their own who, when and how to tell people. At first, I kept it just to my very immediate family and friends. It was something I found very private. It was something that was really about my husband and myself. He was an incredible support but it was ultimately my decision. As I got more comfortable with my decisions I began to tell people and I'm pretty forward and I don't hide much but it took me time to talk.

The other thing that we did was I accept help. That was actually probably one of the hardest things I could have done. But I did accept help from my community. That ranged from picking up my daughter from preschool to accepting a meal or a magazine or a joke left on my doorstep.

Some things were easier during times than others and decisions are often hard. For me, I had my children and I knew we weren't going to have any more so it was pretty straightforward for me. What I can say is that the actual process from start to finish felt long, but as the days went on it was easier and it felt shorter if that makes sense. I can tell you that the day after my silicon implants, I woke up in my own bed and for a moment I actually had forgotten everything. I'd forgotten. I was comfortable. It was over and I knew that I was on a track to moving on.

Where I am today, I can tell you it's a process. I've been through the survivor guilt, the anger, the relief, the deeper appreciation for the opportunity to live a long, healthy life for myself, my husband, my friends and my daughters.

In the beginning one of the things I struggled with, which has been talked about, was trying to put a name on this. Sometimes I did feel like a survivor. Sometimes I felt that wasn't sufficient. I was going through some of the same surgeries and emotions

that some of my friends were going through. At the time I was going through this, I had six friends going through breast cancer surgery, including one of my best friends. I found it really hard to find that right label for myself. The ultimate question, do I wear the pink hat when I walk or not? It was my rabbi who turned to me and said stop driving yourself crazy. You are a survivor in my mind. You dealt with it from the earliest stage possible.

More often than not, I wake up and go about my day and forget about what happened. Hard to believe that it can happen when you're in the middle of it but it does. I would just kind of end with one thing which is it's hard but I joked along the way. That's how I make the best of the moment and it just makes you heal faster.

Shera Dubitsky: Alicia, thank you. That was just wonderfully inspiring and I imagine that your tips of how you went through it will also be very helpful to women who are considering this surgery.

We have had the good fortune of hearing from another Sharsheret caller, Diane Harkavy. Diane called Sharsheret from Memphis, Tennessee several months ago to volunteer to be a Sharsheret link. I found her to be fascinating and upbeat and knew immediately that Diane would feel comfortable speaking with a wide range of women. We are very delighted to have her on board as a Sharsheret link. Diane, the floor is yours.

Diane Harkavy: Thank you. I live in Memphis, Tennessee and I'm going to turn 48 in about a month. My road started when I was about 36 years old. I'll preface everything with the history that my maternal grandmother died of breast cancer at the age of 30. She had her fourth child and she never left the hospital after giving birth to the fourth child and died. The doctors knew that she had breast cancer. But there was nothing they could really do to help her and, unfortunately, that was the time.

In my family, my mother, she was pretty vigilant about when I was growing up about breast testing and mammograms. She went twice a year and I sort of knew about this all the years I was growing up. There wasn't a sense of—no one was really neurotic in my house. Anyway, we were naturally taking care of the situation. In other words, we needed to test ourselves. I got married and I think in my late 20s I

felt something in my breast. I made an appointment, went and had a mammogram. Everything looked great.

I went ahead, my husband and I, and we had four children, four girls. When the youngest child was about a year and a half, I was 36, I felt lumps in my breasts. So I just sort of subconsciously did all these self-examinations and it went on for a little bit of time. I would do it when I was in the shower, when I was laying in the bed at night. I just was checking but I was an extremely busy mother. I had a seven-year old, a five-year old, a three-year old and the baby was a year-and-a-half.

Then it was some woman in the community, actually we were at our synagogue we were having the Jerusalem Day Picnic. All the women learned that there was a Jewish woman in the community that was diagnosed with breast cancer and she was a young woman. She was little older than me but she was still under 40. In my mind I'm thinking, oh my gosh, I need to go check out these little feelings I'm having in my breasts.

So I did. I made an appointment and went in to have a mammogram and I wrote down family history. I wrote down self-examination feeling two lumps. I went in had the mammogram and actually nothing showed up on the mammogram. So just because of the paperwork that I filled out, I was called back to have an ultrasound.

And sure enough, in the ultrasound in one of my breasts there were two nodules or two masses. They didn't know what they were. They said "go home. Let's schedule a biopsy but I'm sure everything is fine." Trust me, I was really not thinking that cancer was in the plans here because I had a lot of kids at home and a husband that really needed me.

Anyway, I went in. I did the biopsy and I had the biopsy, I think, on a Friday morning. On Monday morning, I'm folding laundry and the little one's running around and I get a call and there was a nurse who said she's calling from the mammography lab and that both of the masses were malignant.

So I said, you know, I think you must be mistaken. There's really no possible way. She said, no, you're Diane Harkavy. We went through—I'm sorry ma'am but they're malignant. Well, I hung up the phone. I was shaking. Called my husband, my husband's an attorney. He was in court. Called my mother. Called the doctor and

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by the afternoon I was already at a surgeon's office after calling my gynecologist who set me up there.

I ended up having a double mastectomy. The reason I took the breast that didn't have the masses in it is because the cancer looked to the doctors as though it was pretty aggressive, and they actually recommended that I go ahead and do this. Of course, it was my own choice and it was extremely stressful. It was extremely stressful and new and frightening. But I, thankfully, had tremendous support from my husband and from my family and the actual double mastectomy was pretty much a private thing between my husband and myself. I went ahead and had that done.

I was actually one of the first persons in Memphis to have the sentinel node surgery. Basically, what happens is one of the major nodes is taken out and then a few surrounding nodes and instead of taking many, many nodes from under your arm—I mean, from your breast nodes.

Anyway, the node was clear so, actually, I had elected to have reconstruction. At that time, they put in sort of like water balloons. The process over a few weeks was to inflate them and then eventually have another surgery and put in implants and I chose silicon implants.

After that, I actually had to go through six months of chemotherapy and then five years of tamoxifen. But after my surgery, the oncologist really highly recommended that I go through the genetic testing. I went through the genetic testing and the first results came back negative for the BRCA gene.

Everybody was surprised in the medical side so they recommended I go through a second round of the testing. Sure enough, I came back the second time in a variant category which they weren't really sure what that meant. It was not necessarily negative. It wasn't necessarily positive. What my oncologist had said, if you tested positive, I'm going to highly encourage you to also have your ovaries taken, to have a hysterectomy. We sort of sat on this for a little while. But while the chemo was going on and then after when I was taking the tamoxifen, I started developing some ovarian cysts and they were extremely painful and they went on for a few years.

Finally, the gynecological oncologist spoke to me and said it was her recommendation that I have a hysterectomy. My gynecologist also recommended it

and my mother really recommended it. She was saying, look, you've had your kids and don't play any games. We don't know what it means to be in a variant category as far as the gene pool goes.

Anyway, I went ahead and had the surgery. I was 42 years old when I had the surgery. To me, the removing of my ovaries and my uterus was more dramatic than I had imagined. I have to say that I really wasn't prepared to go through menopause and I did, quickly I guess, so for some that's a relief.

But I was kind of young and I wasn't prepared, I don't think, psychologically to have to deal with libido issues and painful sex and just all sorts of changes in my body. I have to say that I don't think there was a tremendous support system here in Memphis for me.

I read a lot and I'll go on the computer and I'll take out books and I'll ask questions. That worked to my advantage because I found some things as far as supplements, as far as different oils that I took that I don't know whether psychologically they helped me but I felt as though they were helping me both physically, the way I was feeling physically, relieving hot flashes, relieving mood swings, just helping my skin.

So I've had to do a lot of leg work, I think, on my own and I'm just discovering Sharsheret, actually, over the last few months. I think all of you should really take advantage of calling up and getting as much information as you can because it makes it all easier. It makes it all much easier.

After the hysterectomy I always say to people, look, everything takes about a year. After the surgery it takes about a year for your body just to sort of come around and feel like it's your body again. It took me a year after I finished the tamoxifen to really feel like I was me again.

Would I do it again? Yeah, I'd do it again. I feel for anyone who has to do this. I can't say that it's the easiest thing but I live an extremely, extremely full life. I was a ceramic artist for years after that and, actually, after my hysterectomy I decided to go to massage therapy school and I've been practicing therapeutic massage therapy for over a year and absolutely love it.

I lead a really, really hectic life. I have four beautiful girls and we are all healthy. We feel very, very healthy. So I have to say that it's a drag. I mean all of this was really a drag. There were some really, really hard days but you just have to reach out for support from other people. People want to help and people want to make a meal and people want to listen to you, and you need to just do what you have to do in order to live.

That's really, really what it's all about. We live in a fantastic age where changes are happening all the time. The whole nipple reconstruction and saving your nipple—that wasn't around when I was 36 which is only 12 years ago, so constant change and constant new ways of doing things. Anyway, I guess that's it. If anybody has any questions, feel free. Thank you very much.

Shera Dubitsky: Diane, thank you. Your message of ultimately having made a healthy choice really is the takeaway. Thank you so much for sharing that.

Diane Harkavy: You're welcome.

Shera Dubitsky: Tonight's topic was spurred on by the many women who requested that we address this issue. It reinforces the idea that Sharsheret is, indeed, powered by our callers. In light of this, I encourage each of you to complete the evaluation that we will be emailing you tomorrow. Your feedback is critical in helping us to tailor our services and programs to better meet your needs.

Before we begin the question and answer portion of tonight's teleconference, I want to assure you that your identity will remain anonymous should you decide to ask a question. We understand that this discussion may prompt personal medical questions. We encourage you to consult directly with your medical team. Any questions that may come up having to do with hereditary breast or ovarian cancer, please feel free to call us at 866-474-2774 or email us at info@sharsheret.org to speak with our genetic counselor.

Melinda, maybe you can come on and give instructions on how to ask questions.

V. Question and Answer Session

Shera Dubitsky, MEd, MA, Clinical Supervisor, Sharsheret

Operator: Thank you. The floor is now open for questions. If you do have a question, please press *1 on your telephone keypad at this time. Questions will be taken in the order they were received. If at any time your question has been answered, you can remove yourself from the queue by pressing 1. Again ladies and gentlemen, if you do have a question, please *1 on your telephone keypad at this time.

Shera Dubitsky: Thank you, Melinda. Without further ado, the first question we had is for Dina. This is a question that came in prior to the teleconference.

The decision to do prophylactic surgery is often very difficult. It doesn't remove all the risk of developing breast or ovarian cancer, however, it can significantly reduce the risk of developing an invasive cancer in the future. Although we talk about prophylactic surgery, perhaps it is more accurate to be thinking of this as risk-reduction surgery. Dina, what are your thoughts about this?

Dina Roth Port: Well, it's true. No surgery is absolute. With prophylactic mastectomy the risk reduction is by at least 90 percent. Doctors can never be a hundred percent sure they've got all the breast tissue. Breast tissue can reach as high as your collarbone, as low as your abdomen so they can never be a hundred percent sure which is why they say it's not one hundred percent. But keep in mind, the risk is still way below that of the average woman.

For someone with a BRCA mutation, their risk for breast cancer is up to 87 percent in their lifetime. Now you're talking about way below that of the average woman, as low as one or two percent for women who have had the surgery. A study that just came out this year showed that of 2,500 women with the BRCA mutation, none of the women who had a prophylactic mastectomy developed breast cancer during the three-year study. But seven percent of women who didn't have the surgery wound up developing breast cancer.

I guess it, again, is not absolute and the same thing goes for oophorectomy. It greatly reduces risk. It doesn't remove all of the risk. There's always some residual risk but those options will reduce your risk more than any other option out there.

Shera Dubitsky: Great. Thank you. There is the next question. Is it true that Myriad labs is the only lab in the country to test for the BRCA gene mutations? Have you ever heard of an error being made by them in the testing of this? As someone who would normally go

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for a second opinion when diagnosed with something serious, it is unsettling that this is not a possibility if they are the only lab doing such tests.

I posed this question to our genetic counselor and she had said that she never heard of an error. It is overseen by several different people during the testing process and as far as she knows, their protocols are very strict, though, she does agree it is too bad that one cannot have a second opinion.

The next question is, do insurance companies pay for prophylactic surgery for breast and ovarian cancer? Which ones? If yes, what criteria do insurance companies use to pay for these surgeries?

If the woman's risk is high enough to consider prophylactic surgery as recommended by either her surgeon or her medical oncologist, most insurance companies will provide coverage for that surgery because it is not truly considered elective but, rather, it's prophylactic. Most doctors would probably not perform a prophylactic surgery on a woman if she did not have a significant risk of breast or ovarian cancer.

Occasionally we have heard of insurance companies denying a claim, but if the physician provides documentation of the need for surgery, they usually do provide coverage. It helps to have supporting documentation that you can get by your primary care doctor and surgeon.

Also, we have found that surgeons who specialize in breast and ovarian surgery usually have the most experience in getting the cost of the procedures covered by the insurance.

Dina, here's another question for you. How is high-risk defined and is it universal for all insurance companies?

Dina Roth Port: Well, to be honest nothing is universal when it comes to insurance companies. In my book, I have a chapter entitled Money Matters. It's basically all about the cost and the insurance issues that you'll face with all the issues. Not just prophylactic surgery, but genetic counseling and everything you might face when you're dealing with counseling and testing for the BRCA mutation. It was probably the hardest chapter to write because there is no universal answer for that. It really depends greatly on your plan, where you live, which test or procedure you're having, who your doctor is.

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The American Cancer Society recommends that women with a 20 percent or greater risk should get an annual MRI. That's just to give an example and those kind of recommendations are what insurance companies tend to look at so that's just to give you a ballpark. There's no magic number that if you're above 25 percent which is, again, something that a genetics counselor can help you determine what your actual risk is to some degree, there is no exact number, but they could give you a ballpark. Those are the kind of recommendations that the insurance companies look at.

There are organizations like the Patient Advocate Foundation and other organizations like that that can help you with all of these issues, fighting denials and just filing claims and all of that. Because it's very difficult and the key is just to be organized when it comes to all of the cost issues with these surgeries, because it can become overwhelming.

Shera Dubitsky:

Great. Thank you. When a person already has had a hysterectomy for ovarian cancer are there additional consequences to a prophylactic mastectomy regarding sexual function?

I briefly touched on this in terms of the sensation to the breast and we have explored this issue in a previous teleconference on sexuality and intimacy. I certainly encourage you all to look through that.

Generally, what we encourage couples to do, again, is to have open communication. Also, skin itself has a lot of sensation to it. We have found that couples are finding other ways of a woman feeling more stimulated during intimate times with her partner. Again, I would encourage you to go back and look at that teleconference.

Alicia, a question came in for you. How did you make the decision to forego high-surveillance and opt for surgery, ultimately?

Alicia Altmuller:

Well, I think that there were several factors in that. One was my personality. I mentioned that once I found out there was a chance that I might have this and I started to do research. I can't sit still and I had to make all my appointments—knowing me, I had to make all my appointments before even finding out if I was positive or negative because I knew that while I didn't know I was still able to maintain my composure and figured I could make all my decisions as time went on.

When I found out I was positive, I only had a week before I was scheduled to meet my oncology gyn but before that I had done a lot of research. I knew where I was in terms of my stage in life and there were other factors. I've always had problems with—I think ultimately we knew, not because of cancer, but I knew that I would ultimately eventually have a hysterectomy because I had polycystic ovaries and I had some challenges having children. I joke around that I've actually only ovulated twice in my life, one is my daughter Clara and the other one is Miriam and just my own personality of taking control.

Again, there was very little information or experience in my family with breast cancer. I got it from my father's side. It was all men other than a few women in the generation. For example, my grandfather was one of 20, 19 boys and one girl. There is not much history of breast or ovarian cancer and my father was an only child. I'm an only child and it was really just his generation that started. There were only a couple female cousins. But as we went through those female cousins my dad's like, oh, she died of stomach cancer many, many years ago—which, looking back, was probably ovarian cancer. It was basically just my own decision.

The other aspect of it when my husband found out the statistics he turned to me and said, please, let's do everything today. Let's get it all over with. I want you here now. I can't think of tomorrow. So I was very fortunate to have somebody that was willing to go through this, whatever it meant. Again, I think the number one part of it was my personality.

Now, one of the things I will mention is I have friends that have BRCA that have opted for strict surveillance. I had an MRI. When they told me that I would be going for MRIs quarterly, I would have to do them regularly, I would have to self-examination and then go to the breast clinic for regular things, I just felt like that was just too much. And there was too much of a risk for me. I stress that I chose the hysterectomy. I think that a lot of it is we talk about is the breast cancer or the risk of breast cancer when there is also a huge risk of ovarian cancer and the silent killer.

One thing I will say is that I did not know this at the time, but my cousin was very quiet because her best friend had a cousin who was going through the exact same thing as me and we had our hysterectomies within weeks of each other. My cousin's

best friend's cousin, both of us were BRCA and mine turned out to be benign and hers, she was stage III.

There is no telling what—again, there is no comfort in either decision. Mine, I could have been the stage III. I could never get it and that's—but for me just knowing that and being able to be available to help my friends as they go through it or be able to run with my daughter or be able to have a nice dinner with my husband, those are things that helped put more weight on the decision to do that.

Shera Dubitsky: Great. Thank you, Alicia. Dina, what are the pros and cons of going with a long-standing gynecologist versus seeking a gynecological oncologist? In your experience is there a difference in procedures between the gynecologist or the gynecological oncologist in performing surgery?

Dina Roth Port: Experts tend to recommend going with a gynecologic oncologist. They are specifically trained to find cancer. However, one of the women in my book, Rori specifically, interviewed gynecologic oncologists and then decided to go with her longstanding gynecologist to have her ovaries removed because she felt comfortable with him. He delivered her three children and that was the right decision for her.

However, if you do choose to go with a gynecologist, when you're interviewing different ones or speaking to your current gynecologist you want to make sure that if they're performing the surgery and find any kind of cancer whatsoever that they would then bring, obviously, a gynecologic oncologist, have one standing by to help with the surgery so that's important.

Again, if you go to the two organizations at least you're finding reputable doctors, the two that I mentioned, The American College of Obstetricians and Gynecologists and the Society for Gynecologic Oncologists. So either way they'll help you find reputable doctors and then you go with what you feel is right for you.

Shera Dubitsky: Great. Dina, we have another question for you. In terms of your research and interviewing people have you ever seen someone who was a previvor who tested positive for the BRCA gene, who had the surgery, they found malignancy, and now went from doing something that was prophylactic to doing something that was in full-blown reaction to now having cancer?

Dina Roth Port: None of the women that I interviewed had that situation. I believe Alicia was telling a story earlier, I don't know if you want to tell it Alicia, about that happening to someone that she knew. Usually before you're having prophylactic surgery you're seeing your doctor regularly for screening beforehand to see if cancer has developed before your surgery and at that point then, obviously, it wouldn't be considered prophylactic surgery any longer. But I mean, that does happen. I haven't come across it too often and it wasn't the case of the women in my book. But cancer can strike at any time so, of course, that could be the case.

Shera Dubitsky: It is standard practice for the tissue to be tested, even for women who are doing prophylactic mastectomies or oophorectomy, hysterectomies. We have certainly received some phone calls at Sharsheret from women who had the tissue tested and it turns out to be malignant. So certainly, if you find yourself in that situation, we encourage you to call Sharsheret and we can find you a link that you can talk with, who's in that similar situation.

There was a question that came in revisiting the nipple and skin-sparing. We're hearing that it's more common in Europe. Dina, do you have a sense of why it's not as common of a surgery here in the United States?

Dina Roth Port: I think one of the plastic surgeons I interviewed for the book told me that when it comes to surgery, in general, it's kind of like trying to turn a battleship. It just takes a very long time for things to come into place. For instance, it used to be radical mastectomies were kind of the norm and now skin-sparing mastectomies are becoming more and more common along with nipple-sparing but it's going to take a long time before those become mainstream. It takes a long time for the insurance companies to get on board and for more and more doctors to become trained in the different surgeries which is usually a big part of it is that's it's a relatively new surgery. Same thing with these one-stage surgeries, they're pretty new and cutting-edge. A lot of doctors haven't been specifically trained in them and they're going to do the surgeries and recommend the surgeries that they feel comfortable with.

That's why it's important to go to organizations like Sharsheret to find different resources and do your homework, you have the time to do homework and to find the surgery that's right for you and then the doctors who do perform them.

Shera Dubitsky: Great. Diane, did you feel that your doctor prepared you well about the menopausal symptoms? What tips can you give to women in terms of asking the questions that may be helpful prior to doing that surgery?

Diane Harkavy: Actually, I probably skimmed that and that's pretty important. I actually don't think that the doctor really prepared me for what I was going to experience. I have to be honest and I probably didn't ask questions. I didn't ask enough questions. Please, when you're going to do this like the other women say, you must, must do your research and you must read as much as you can as far as what's going to happen after the surgery.

For instance, I really was told nothing about bone health. It wasn't until a couple years after I had my hysterectomy that the oncologist decided to bring up having a bone density test and by that time I had already developed osteoporosis and I was really actually pretty aggravated.

We know now that taking different supplements and eating certain amounts or actually taking in a certain amount of calcium. I mean, really being aware of what you're doing, what you're consuming in your body, what's being absorbed, that kind of knowledge, I think, is really critical and is a little adjustment to your lifestyle but can prevent things like loss of bone.

Shera Dubitsky: It sounds to me that, perhaps, if women do the research and speak to people who have been through this experience, it may give them direction in terms of what kinds of questions to ask.

Diane Harkavy: That's what I'm saying. Everybody isn't a researcher by nature and it can be a very emotional and overwhelming thing to be told you have to have a hysterectomy. You have cancer. You need to remove this organ. You need to remove that organ. Everybody isn't always as organized as they would like to be and really understands, okay, great you're going to take my breast, you're going to take my ovaries, you're going to take my uterus. But guess what, afterwards you're going to have major hot flashes. You're going to have major mood swings. You're going to gain a lot of weight. There's all sorts of issues.

I think a surgeon is a surgeon and an oncologist is really dealing with numbers and where you fit into what your pathology says and what the procedure is for your

pathology. But you're a person and there's a lot of living that has to go on and that's why you have to ask a lot of questions.

VI. Teleconference Conclusion Closing Remarks

Shera Dubitsky: I encourage all of you, again, to call Sharsheret and to do the research.

We've received a lot of questions and we would love to continue this conversation on our blog to discuss this. If you have further questions please call us tomorrow at the Sharsheret office and we can try to address them.

There were many questions that came in having to do with genetics and some specific medical questions. Again, I want to encourage you to go back to your medical team and to speak with a genetic counselor to really get accurate information based on your own individual variables.

Please remember that you can reach us at any time toll free, 866-474-2774 or you can go to our website, www.sharsheret.org. Please remember to complete the evaluation.

We'd like to thank The Gorlin Family, the Julius and Emmy Hamburger Memorial Fund, the Stephanie Sussman and Ann Nadrich Memorial Fund. I'd like to thank Adina Fleischmann for formulating and coordinating tonight's teleconference.

Dina, again, I'd like to thank you for your thorough research on this. Alicia and Diane, thank you so much for sharing your personal stories with us and giving us insight. I think both of you really gave us some very important tips. I want to thank all of you for participating this evening.

Good night.

Operator: Thank you. This does conclude today's teleconference. We thank you for your participation. You may disconnect your lines at this time and have a great evening.

VII. Speaker Bios

Shera Dubitsky, MEd, MA, is the Clinical Supervisor at Sharsheret. Prior to joining the Sharsheret staff, Shera worked as a researcher at Memorial Sloan-Kettering Cancer Center. Shera assists women newly diagnosed and at high risk of developing breast cancer, provides supportive counseling to women living with metastatic breast cancer, and lectures nationally on topics addressing the needs of women facing serious illness.

Dina Roth Port is a freelance writer, journalist, and author. Her book for women at high risk for breast cancer, *Previvors: Facing the Breast Cancer Gene and Making Life-Changing Decisions*, was published by Penguin in October 2010. Dina's writing has also appeared in many national magazines such as *Glamour*, *Self*, *Parenting*, *Cosmopolitan*, *Natural Health*, *Fitness*, *Martha Stewart Weddings*, and *Prevention*. A graduate of Northwestern University's Medill School of Journalism, Dina first worked as a health editor at *Glamour* magazine. There she wrote and researched pieces on breast cancer, colon cancer, depression, abortion, eating disorders, and autoimmune diseases. As an editor at *Parenting* magazine, Dina worked closely with pediatric expert Dr. William Sears on his monthly column and features.

VIII. About Sharsheret

Sharsheret, Hebrew for “chain”, is a national not-for-profit organization supporting young women and their families, of all Jewish backgrounds, facing breast cancer. Our mission is to offer a community of support to women diagnosed with breast cancer or at increased genetic risk, by fostering culturally-relevant individualized connections with networks of peers, health professionals, and related resources.

Since Sharsheret’s founding in 2001, we have responded to more than 24,000 breast cancer inquiries, involved more than 1,400 peer supporters, and presented over 200 educational programs nationwide. Sharsheret supports young Jewish women and families facing breast cancer at every stage—before, during, and after diagnosis. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life.

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
- *Busy Box*, for young parents facing breast cancer
- *Best Face Forward*, addressing the cosmetic side effects of treatment
- *Sharsheret Supports*, developing local support groups and programs
- *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

Education and Outreach Programs

- *Health Care Symposia*, on issues unique to younger women facing breast cancer
- *Sharsheret on Campus*, outreach to students on campus
- *Facing Breast Cancer as a Jewish Woman*, an educational resource booklet series

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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