Surviving Breast Cancer: Facing the Challenge

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Presented By:

Sharsheret®

Linking Young Jewish Women in Their Fight Against Breast Cancer

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I. Introduction

Shera Dubitsky, MEd, MA Clinical Supervisor

Shera Dubitsky: Thank you for joining us this evening for Sharsheret's Teleconference, *Surviving Breast Cancer: Facing the Challenge*. My name is Shera Dubitsky and I am the Clinical Supervisor at Sharsheret.

I will soon have the pleasure of introducing our distinguished speakers, all of whom will share their insights into what has become a critical subject to those affected by breast cancer. Namely, I've finished treatment, now what? The inspiration for this Teleconference came about as a result of several converging factors. I had begun to track the number of phone calls I've received that focused on post treatment issues and the calls often went something like this: "When I was first diagnosed, I didn't know what to expect or how I would get through this. I was okay as I went through surgery and treatment, but now that treatment is over, it's hitting me emotionally."

As many of you have experienced first-hand through some conversations with me, my typical response to this is: "Well, I'm relieved to hear that you're experiencing an emotional hit. Really, what rational person doesn't take an emotional hit in the context of an irrational situation? The fact that you are having an emotionally difficult time is a good sign that your mental health is intact." I have also fielded many calls from women focusing on medical questions. Who monitors me now that treatment is over? How often do I need to be screened? I keep hearing that there's a plethora of research going on in the world of breast cancer, what impact can this have on me? How do I get my sexual libido out of the freezer? When can I safely begin trying to get pregnant? Is chemo brain real?

Some women have called Sharsheret struggling with survivorship as a Jewish woman. The word survivor itself conjures up references to the Holocaust. Perhaps Jewish rituals and milestones hold a different meaning for some of you.

Another inspiration for offering this Teleconference came on the heels of a phone call that I had with a Sharsheret caller. She said that she was diagnosed with cancer five years ago in her mid-thirties. Today, friends and doctors congratulate her on being a survivor but she hates that term. Her mother who has had cancer two times says, "You can call me a survivor when I die of something else." This caller also said that she was tired of the pretty face and pink ribbons that were being portrayed in the breast cancer world. She wanted to have a forum where women can say, "You know what? Cancer is not pretty. Cancer is hard. I can't always wear a mask of strength portraying a stiff upper lip. Survivorship isn't easy." We wanted her voice to be heard, and judging by the number of participants on this call representing 13 states across America, in addition to Canada and Israel, hers is clearly not the only voice struggling with these issues.

The final variable that influenced our choosing this topic followed my having read the book by Shelley Lewis, one of our speakers this evening. She truly captured that caller’s sentiment with honesty and humor. I found myself quoting her and referencing her in many of my phone conversations with women calling Sharsheret.

Tonight's Teleconference will be addressing these issues and offering some suggestions and guidance that may help you post-active treatment. I also encourage you to call Sharsheret for further support and resources. I will give you that contact information at the end of the Teleconference.

There will be a question and answer period following the presentation. I strongly urge you to complete the evaluation form. We will be emailing you a form that you can complete on-line or you can complete the evaluation form found in your Teleconference packet. Our programs are driven and inspired by feedback from Sharsheret callers. It's important that we continue to tailor our programs based on your needs.

It is now my privilege to introduce our first speaker, Dr. Ruth Oratz.

Dr. Oratz is the Founder and Director of the Women's Oncology and Wellness Practice in New York City, specializing in treating women with breast cancer and other malignancies and those at risk for cancer. She has been an active member of Sharsheret's Medical Advisory Board since Sharsheret was founded in 2001. Dr. Oratz has often presented at Sharsheret events and has been gracious and generous with her time and wisdom, and for all of this, we are truly grateful.

Please join me in welcoming Dr. Ruth Oratz.

II. Long-Term Side Effects of Breast Cancer Treatments.

Dr. Ruth Oratz,FACP

Dr. Ruth Oratz: Thank you very much Shera and thank you to all of the women who've called in this evening to participate and take time out of your schedules. My assignment for tonight is a big one for 15 minutes and I am going to try to touch on as many of the issues that relate to the long-term effects of treatment for breast cancer.

I think the first question that enters every woman's mind when she has a diagnosis of cancer is, will I live? And the next question that comes to mind is, how will I live? Will I live well? And that's really what we're addressing in this evening’s Teleconference.

There are many, many aspects to breast cancer treatment. There's surgery, there may be radiation therapy, some women undergo chemotherapy and hormonal therapy, or variations and different combinations of all of those modalities. Each one of those modalities and each step along the way of breast cancer treatment, carries with it side effects. Some of those are very short-term and very short-lived. They will be over with very quickly. Some of those side effects may last a little bit longer, and then there are some really long-term consequences of receiving the diagnosis of breast cancer and undergoing treatment. These relate to our physical well-being, our psycho-social well-being, and our emotional health. I am going to try and address some of these. Of course, I won't be able to go into a lot of detail, but I will just try to outline them.

Let's think about the surgery first of all. That's very, very often the first step in treatment when a woman learns that she has breast cancer. She may have some biopsies and all kinds of imaging tests, and then usually some kind of surgery is involved, whether it's a lumpectomy, or a mastectomy with or without reconstruction, and there are different kinds of reconstructive surgery. The lymph nodes under the arm may be removed, perhaps just with a sentinel node biopsy. In other cases, more lymph nodes may be removed. Whatever type of surgery you undergo, there's the immediate aftermath of surgery which may include some post-operative pain or issues related to the scar.

More long-term, we have to think about range of motion of the arm and the shoulder, making sure that you can move freely and comfortably. We want to know that you've healed well. We want to discuss residual pain. Women often tell me, even a year or two years after their surgery, that they still feel some discomfort in that area. That's normal.

Scar tissue takes a long time to heal. There are some women who will develop lymphedema, or swelling of the arm, if they've had surgery under the arm particularly if radiation therapy is also given. That's a physical consideration after surgery.

But there are other things that happen when we have surgery on our breast that aren't only physical. There are body image issues and sexuality issues. You may lose partial or full sensation in the nipples, even if you breasts look beautiful after the operation, or you've had a great reconstruction, you may not feel the same about your body as you did before surgery. These are all issues that we have to think about and deal with. If you undergo radiation therapy there are the immediate side effects which may be fatigue and some skin changes, particularly redness to the breast. Those things get better usually in relatively fast order, but as I mentioned, there could be an exacerbation of lymphedema of the arm or swelling of the breast, or the size of the breast may be a little bit different after surgery and radiation. It may be larger, it may be smaller, depending on the circumstances.

Very, very rarely there could be complications that involve a sliver of the lung or some exposure of the heart muscles to the radiation, but as many of you know, there are a number of new techniques now that are being explored and being looked at to minimize the exposure of radiation to the heart and lungs and other organs. Surgery and radiation therapy have some short-term side effects and some long-term side effects. Those relate mostly to physical issues, body image, and sexuality issues.

The other treatments that we use in breast cancer, chemotherapy and hormonal therapy, have a completely different set of effects on the body, on the psyche, and on the emotions. Women who undergo chemotherapy for breast cancer, and many of our young patients have to face chemotherapy, of course have to get through the treatment itself which can be quite difficult. It is the real deal when you get chemotherapy. I think one of the most dramatic things for a woman of any age, is the possibility and the thought of losing her hair. Many Jewish women cover their heads and either wear a wig or a head covering. One might say, “Oh, then it's no big deal if you lose your hair.” Not true. It's a really big deal. Maybe to the outside world you don't look so different. But when you look in the mirror when you come home at night and you close that door behind you, when the public face is off, confronting your hair loss or having your family see you is very difficult. It is a very, very big deal and one that is not to be underestimated. Hair grows back, but I would not underestimate the impact that has on you as you go through the experience.

Fatigue is a very prominent component of treatment during chemotherapy. Chemotherapy may be finished in as short as 12 weeks and it may go on for as long as 6 months or more. Chemotherapy can cause decreases in the blood counts, the white blood cells and the red blood cells. All of that can contribute to the fatigue as well as the de-conditioning that comes with the treatment. When you’re feeling fatigued or feeling a little bit nauseated, or you're just not feeling like your usual self, you're not going to be as physically active as you would normally like to be.

Some women gain weight, some women lose weight during treatment. All of this can take a very, very long time to resolve. It takes months and months after treatment is finished before you feel like you have your own physical self back again. Your sense of taste and smell may be altered during chemotherapy. The foods that you enjoyed before chemotherapy may not seem enjoyable again for a long time. You may like a glass of wine once in a while and you may not have a taste for that. That should get better and come back over time.

What are some of the other more long-term implications of chemotherapy that might even take a bit longer to resolve? Is chemo brain real? I think the answer is yes. I think it is real. It's very difficult to quantify the impact of treatment on our cognitive functioning or on our ability to think fast, to think on our feet, to do mathematics, or to have a sharp memory of everything you need to get done during the day. That gets a little bit blunted during treatment and there are many factors that contribute to that.

Part of it is just the whole psychological, overwhelming experience of getting this diagnosis. Coping with it and trying to continue with your normal life, your work life, taking care of your home and your family, relating to your friends and your community, while at the same time you are going through treatment and you are concerned about yourself.

The cognitive functioning, as I said, is difficult to quantify but it is real. Most women do experience some change in their ability to multitask and to do all the zillions of things you normally do. I think in most cases, it gets better and usually gets back to normal. But it could take a while and it varies from one person to the next.

There are some very specific consequences of chemotherapy treatment that also may not resolve completely or may take a long time to get better. Some drugs can cause neuropathy or tingling in your fingers and toes. If it's more severe, that could lead even to numbness in the fingers and toes. Generally, that gets better with time. Sometimes it can take a very long time. I've had patients tell me that they feel discomfort in their feet, almost like a burning sensation. Even for 6 months or 8 months after their treatment is finished. But generally, by a year later, they feel much better.

There are some more rare complications of chemotherapy that may affect cardiac function, the heart muscle, again, depending on which drugs you may have had. We watch very, very carefully and monitor the cardiac function but in some incidences there can be some decrease in cardiac function which may or may not be reversible. And very, very, very rarely, but not impossible, is the chance of developing leukemia after chemotherapy treatment. As I said, it is an unusual complication, it's rare, but it does occur.

For young women who go undergo chemotherapy, fertility is a major issue. Some of you may have had children before getting treatment and some of you may not have. Depending on your age, depending on the other hormonal issues going on in your body, you may or may not be able to have a normal conception after completing chemotherapy, and of course it also depends on whether or not you need to be on hormonal treatments after your chemo is completed. Issues around fertility and what you can do before starting treatment to help preserve the opportunity for future child bearing or having embryos or eggs preserved or frozen in advance, is something that should be taken into consideration for young women who are facing chemotherapy. These are very serious issues and important family decisions. Again, we don't have a lot of time in this brief presentation to dig into those details but is certainly something that needs to be addressed.

There are many issues related to hormonal therapy. Some of the side effects are just the side effects you feel during treatment. For many women, those are the symptoms that are menopausal symptoms: hot flashes, not having your period, vaginal dryness, or vaginal discharge. We have to think about the health of the bones after chemo and hormonal therapy, including monitoring bone density. Again, we have to think about cardiac health and whether or not there are risks of blood clots, strokes, or heart attacks. We monitor the cholesterol level.

After all of these treatments, not just the physical side effects, but the psychosocial impact and the emotional impact of treatment affects each woman in a different way. Our body image changes, our sense of ourselves, our self image in terms of how we relate to people we're close to, our partners, our family members, our colleagues at work, our friends in our community, all of these change. Sexual functioning changes.

Your libido will undoubtedly not be the same during treatment as it was before. Will that come back to normal? There are many, many, many factors that will impact functioning once treatment is completed.

I think the most important lesson that I've learned after working with so many women in the last 20 years that I've been in practice, is that we have to talk to one another. You have to tell your doctor, your nurse, your social worker, anyone who is part of your healthcare team, tell them how you are feeling, raise your concern even if you think it's a crazy question, even if you think it's unrelated. Ask us. We may not know the answer. Hopefully, if we don't know the answer we will be doing some research and trying to find out the answer for you. There may be something we can do to help you feel better, or to help direct your concerns, or to help make sure that we've addressed it in advance if it's an issue or concern that you'd like to raise before beginning therapy. Communication is the most important part of your on-going therapy with your healthcare team.

Diet and exercise are also very, very important. What you eat, to some extent, is going to determine how you feel, building up your strength. There are some foods that we want you to eat, we will encourage you to eat, and some things we don't want you to do. We know that obesity is linked, certainly in post-menopausal women, to an increased chance of breast cancer and breast cancer recurrence. Although diet alone isn't the only factor that affects things, it is very important. As I mentioned before, some women gained weight during treatment. Some women lost weight. We'd like to get you to your ideal body weight with a healthy, well-balanced diet. And that's true of exercise also.

Some of you come into treatment having already been on an established on-going exercise program and others of you have not been. Some people are more active just naturally than others. Our lives have many demands on our time and our level of activity. But it is important to stay active and to do as much as you can, both during treatment and then after treatment, as your strength re-generates, as you become less fatigued, and you start coming back to yourself. Physical exercise is very, very important and in fact, there's increasing data now in the literature that is being published that shows that women who engage in physical exercise, really in almost any type ranging from yoga to jogging, will derive some benefit from that exercise, whether it just means that you feel a little bit better or it actually helps to reduce the risk of recurrence.

In wrapping up, I just want to highlight some of the big issues that we should think about. The side effects that you will experience during treatment are short-term, medium-term, and long-term. Each one of these treatment modalities has its own set of side effects and implications to go along with it, surgery, radiation therapy, chemotherapy, hormonal therapy, and the new biologic agents that we are using in treatments as well. I would encourage you to ask as many questions that you can in advance of starting your treatment, during your therapy, and afterwards in your on-going relationship with your healthcare providers.

Shera Dubitsky: Thank you Dr. Oratz. I'm convinced that your knowledge and insight will serve as a springboard from which women can address these issues with their medical team.

It is now my pleasure to introduce Dr. Tessa Cigler.

Dr. Cigler is the Assistant Professor of Medicine at the Weill-Cornell Medical Center and Attending Physician at New Your Presbyterian Hospital. Dr. Cigler's practice, located at the Weill-Cornell Breast Center, is dedicated to the care of women with breast cancer. She has a particular interest in issues of survivorship and fertility. As a clinical investigator, her research focuses on optimizing hormonal therapies and on novel therapies for both the treatment and prevention of breast cancer.

We want to thank Dr. Cigler for so graciously agreeing to discuss emerging research on post-treatment options.

It's my pleasure to now introduce Dr. Cigler.

III. Emerging Research on Post-Treatment Options

Dr. Tessa Cigler, MPH

Dr. Tessa Cigler: Good evening everyone. I'm honored for the opportunity to speak tonight.
I think that survivorship issues are one of the most important areas in breast cancer treatment. I hope that these issues remain a focus of on-going research and attention in our community.

As more and more women are diagnosed with breast cancer, increasing numbers of women are alive after their diagnosis. In fact, there are over 2 million women in the United States alone who are current breast cancer survivors. Increasing attention is being paid to post-treatment or survivorship issues among women with breast cancer.

The National Cancer Institute has defined a cancer survivor as a patient who has completed their active therapy. To highlight the importance of survivorship, the Institute of Medicine and the National Research Council have recently issued a report appropriately entitled, *From Cancer Patient to Survivor, Lost in Transition*.

To avoid being lost in transition, as so many of our patients feel, they have a few recommendations. For one, they recommend that medical providers outline a survivorship care plan for their patient at the end of active treatment. This is a written summary which should include the type and the stage of cancer, the treatment received and common side effects, a schedule of follow-up visits and testing, and on-going screening following a breast cancer diagnosis. Other than routine mammograms, there's not a lot of other screenings that are usually recommended. The survivorship plan should include suggestions for maintenance of good health. Of course, this plan should be communicated to the patient as well as to her other doctors. The Institute of Medicine also recommends that a medical practice nurse identify and manage late affects of treatment including the physical, emotional, job, and family related issues.

What has struck me in my practice is when a woman finally completes her treatment, either radiation or chemotherapy, I am feeling relieved and excited. Yet, for the patient, that is often the very moment when many of these survivorship issues, particularly the emotional struggles, begin. All of the patient's energy has previously been focused on just making it through treatment and then suddenly, her attention switches to larger issues.

In my mind, there are immediate and late issues which face breast cancer survivors. One of the most important immediate issues is the fear of recurrence. This is such an important issue and is often so difficult to deal with. Dealing with the physical changes and the symptoms after breast cancer treatment, along with fatigue and depression, are also key concerns. Cognitive dysfunction, including memory and concentration loss, and what my patients say is just the inability to multitask, weighs heavily on women's minds.

Weight gain can be an issue, as well as many effects of estrogen deprivation syndrome, be it from chemotherapy-induced menopause or from hormonal therapy: hot flashes, sleep problems, and sexuality issues to mention just a few. From many of these same issues, other issues appear a little bit later.

For younger women, fertility and pregnancy are major issues as is estrogen deprivation. The side effects of maintenance medicine, such as Tamoxifen or the aromatase inhibitors, such as joint pain, can be very significant. Bone loss and osteoporosis can be particularly troublesome as well as the cognitive dysfunction. Women worry about the long-term effects of chemotherapy and of course the challenges that face women as they have to return back to the workforce.

So what can be done to address some of these issues? Well, this is an on-going question and we don't have perfect answers for it. Certainly fertility issues need careful planning from the very beginning of treatment. Schedule consultations with reproductive endocrinologists to discuss options for embryo or egg preservation, which has to be done before chemotherapy.
And for women planning pregnancy after treatment, the appropriate timing and recommendations need to be carefully discussed with their treating physician.

The estrogen deprivation syndrome can be so difficult to treat. There are some pharmacological medicines that can be used to treat hot flashes, including anti-depressants. But caution has to be taken because several anti-depressants can interfere with Tamoxifen. So for women on Tamoxifen, carefully discuss this with your treating physician. Vaginal dryness and decreased sexual libido can sometimes be treated with lubricants and moisturizers and sometimes vaginal estrogen can be used. Anytime that is considered, this has to be carefully coordinated with the physician.

Bone loss becomes an important concern of young women who have premature menopause, either from chemotherapy or from ovarian suppressing medications. The aromatase inhibitors, which are increasingly used in post menopausal women, can be associated with bone loss. Bone loss can be screened for with bone mineral density or DEXA scans. Every woman, after treatment, should be counseled on weight-bearing exercise and adequate calcium and vitamin B supplementation. Bisphosphonates are a class of medication which have proved very effective in both treating and preventing bone loss.

What are the lifestyle concerns which we can address? Diets that tend to be good for overall health also tend to be good for breast cancer risk. There have been some studies showing that some diets low in saturated fat and high in fruits and vegetables may decrease the risk of breast cancer recurrence. Likewise, even moderate exercise, as well as maintaining a healthy body mass index or a healthy weight, has been shown to decrease the risk of breast cancer. Areas of active study include the use of bisphosphonates, the bone strengthening agents I spoke about for treatment for osteoporosis, are being actively explored in large randomized trials as prevention therapy for preventing breast cancer recurrences. Also, the role of vitamin D in breast cancer recurrences is being actively looked at.

In conclusion, the optimal and most effective ways to manage the survivorship issues remain an area of active research. The increasing numbers of survivors and the increased awareness of survivorship issues, presents a great opportunity for ongoing research. For now, I strongly feel that medical practitioners owe it to their patients to recognize these post-treatment problems, with close follow-up as women transition from patients, from having treatment, to being survivors. Medical practitioners should also partner with our patients in developing a dynamic survivorship care plan. This should include collaboration with other physicians and working groups and also seminars and forums such as this one.

I'm going to end by quoting the front cover of Vogue last month on which the following headline occurred, "Life After Breast Cancer Not Just Surviving, But Thriving." Thank you all for your attention.

Shera Dubitsky: Thank you Dr. Cigler. We appreciate you giving us a window into some of the interventions addressing the medical side effects. I want to remind everybody that if you have any questions for any of the speakers, you can call them in after the presentations.

It is now my pleasure to introduce Shelley Lewis author of the book, *Five Lessons I Didn't Learn from Breast Cancer and (One Big One I Did)*. Normally I would be peppering my remarks with quotes from her book, but fortunately, tonight we have the real thing. I've managed to reference her in conversations with callers, in a presentation on genetics, and even during a lecture on the holiday of Simchat Torah. And trust me, this was a stretch, but I just couldn't help myself.

We want to thank Shelley for agreeing to present this evening. Shelley, the proverbial floor is yours.

IV. Facing Life after Breast Cancer Treatment

Shelley Lewis, Author

Shelley Lewis: Thank you and it was nice to hear the remarks about the cover of Vogue because my book and I were mentioned in that article about thriving after breast cancer. So it was lovely that I was in Vogue without even having to have liposuction. I never thought that would happen.

I'm going to be a little different, ladies. I am not a doctor and I don't play one on TV or on teleconferences. I'm just going to tell you how it was for me and how I'm getting on 4 years later. Recently, I moderated a panel for breast cancer patients, past and current, that was entitled, "Who am I now?". I think they asked me because they knew from my book that I'm not sold on the notion that breast cancer made me a different person. I wasn't entirely sure that the question had to be answered as anything other than: Who am I now? I'm me, I'm the same me as before. But I was definitely in the minority in that opinion.

From the beginning, I refused to take breast cancer as seriously as I should have. I was lucky enough to have an early stage, very small tumor and after the lumpectomy, I went to Italy. Well, actually, first I had my hair done the day after surgery, literally the day after, because my roots needed to be done. For the longest time, I convinced myself that cancer barely laid a glove on me. Chemo, of course, was another story. But it was my goal not to let breast cancer slow me down, or change me; except it does eventually.

After I unpacked my feelings, which had been buried for two or three years, I realized that I was angry and I was frustrated. When I was writing my book, I came across a quote from Dr. Susan Love, the brilliant breast cancer surgeon and researcher. She said, and I'm quoting, "Once you're diagnosed with breast cancer, you become an outsider. You no longer belong to the world of the temporarily immortal, but have joined the world of the defective." I didn't know it when I was going through it. But looking back a couple of years later, I can see truly that is the crux of the issue.

I just wanted to be the real me, the insider, and not, as she put it, an outsider. I was nowhere near ready to consider mortality or getting older. I just wanted to keep going on with my life, which I was enjoying. And most important, I did not want to become part of the permanent cancer community. I have said the cancer club is a perverse organization where you have to pay your dues to get out, not in.

Susan Sontag wrote in Illness as Metaphors, that each of us holds dual citizenship in the kingdom of the well and the kingdom of the sick. But I didn't feel that I belonged to either of those two kingdoms. I clung to my home in the land of the healthy. And I refused to believe the resident who told me rather gently, but persuasively, that I couldn't live in Healthy-ville anymore. It was shattering to my ego and to my sense of self.

I had spent my whole life there. I had a great place. I knew where all the best shops and restaurants and schools were. And I was happy in Healthy-ville. Couldn't I just get a short sublet in Breast Cancer World briefly, and then move back to my old place when I'd finished treatment? I could not imagine how I could possibly live in Breast Cancer World. But since it felt like the whole planet expected me to move there, I reluctantly gave it a try. I felt pressured to go meekly into the pink ghetto, but I could not stay there. I felt like an alien. I couldn't breathe. I couldn't find sustenance; I couldn't wait to get out of there and back to Healthy-ville, even if I had to pass to blend back in with the people there. Now the truth is, I'm not so much living large in Healthy-ville as I am hunkered down on the outskirts, living on the wrong side of the tracks. In my new and far less pleasant neighborhood, I get stomach upset a lot, pretty much every time I eat raw vegetables. Luckily, it's cured by popping a Tums. All of the little freckles and nodes that I've had for years can be melanoma in the middle of the night until my dermatologist tells me that they're absolutely nothing. I don't want to be a hypochondriac, but the mind does go there after you've had breast cancer. Every six months, I have the heart-pounding, sweat-inducing nightmare of mammograms and sonograms which, too often, have turned up something that needs further checking out. But so far, thank God, have not found anything too serious.

Speaking of sweat-inducing, the drug that I used to take, Tamoxifen, made me sweaty every day; now Aromasin is doing pretty much the same thing. I'm always too hot, which is not the same as having hot flashes (which I know from experience). But it's only marginally less embarrassing to be constantly flushed and damp than it is to have it come on with a dramatic and unexpected flourish. Half-moon shaped sweat stains around your neckline look kind of great in the gym, but in the office, not so much.
The bars here in the edge of Healthy-ville have a one drink limit. If you're diligent about minimizing your risk of recurrence, you take seriously the possible relationship between alcohol consumption and breast cancer. The same goes for soy products. “Bye-bye, Boca burgers and Sayonara, tofu. I loved you but..."

And then there are those obsessive self-exams. I'm like a 16-year old boy around my breasts, constantly feeling myself up. I search every square inch for lumps, which is ironic, considering the fact that I never felt my tumor when I actually had one, or the benign growth that I had in the other breast the following year.

And, yes, my part of Healthy-ville has an over-abundance of plus-size stores for those of us who have become over-abundant in the butt and thighs. I don't blame Tamoxifen or the other drugs I take for the ten pounds that I've gained, but I do blame it for making it almost impossible for me to lose the weight. There is no scientific proof, I realize, that Tamoxifen or the other hormones, the aromatase inhibitors, cause weight gain. But it's such a common, almost universal complaint, that I have to say, if it walks like a duck and it quacks like a duck, it is probably a woman on Tamoxifen. And in any case, we just move on trying to accept our bodies however they are- fat, thin, lop-sided or even.

The expectations for women who have had breast cancer are mind-blowing. Either people expect you to get on with your life, get over it and move on as soon as your hair grows back or your implants are implanted. Or they expect you to be bathed in a pink aura, a survivor who lives in the pink bubble. Why that is, I can't say. We are all these walking symbols, the brave, plucky women who have had this great and ennobling experience. I hate that. Did you ever hear someone, usually it's a celebrity or some other rich person, say getting cancer was a gift? The first time I heard it, I must confess, I was a little bit shocked. I had no idea. I was embarrassed. Where are my manners? Except that I don't know who I should be thanking for this gift, environmental polluters, my mom and dad? I'm so confused. To tell you the truth, when my gift arrived it seemed more like junk mail that was just waiting for me to pay attention to it, like a five-pound catalog from some auto parts chain or the September issue of Vogue.
I never believed the old adage, it's better to give than receive until I heard about the gift of cancer. I mean, we've all gotten bad gifts from time-to-time. But if you think cancer is a gift, you must really have a closet full of bad stuff. If you think cancer is a gift, I hope you saved the receipt. If you truly believe cancer is a gift, please do not come to my next birthday party. You've probably figured out that of all of the maddening ways in which people try to search for meaning in the random meaninglessness that is breast cancer, nothing annoys me more than the women who declare that breast cancer is a gift. To me, it's the social pressure to be the good, cheerful survivor taken to its extreme. Can't we all just get through a life crisis without receiving a gift at the end to make it all worth it? Is diabetes a gift? Is heart disease a gift? Or is it only a consolation prize for those of us playing who-wants-to-be-a-breast-cancer-survivor? I've said that every woman should be able to do whatever it takes to get herself through breast cancer. It's not up to me or anybody else to judge her. And I'm not judging women who say that breast cancer was a gift for them, but I am compelled to point out that those women were given the greatest gift of all and that is good luck. They were lucky enough to have a curable cancer. Maybe they consider breast cancer to be a journey of self-awareness or enlightenment, but for tens of thousands of other women every year it's a journey to tragedy. They're the ones who have suffered through multiple rounds of surgeries and chemo's, who fought just as hard, who were just as brave, who deserved to live just as much, but didn't. Breast cancer was not a gift to them, nor to the loved ones they left behind.

I'm certain that the heart-felt proclamations about the gift of cancer are meant to be inspirational and they probably do inspire some women, which is great. I wonder, though, how many are inspired to believe that they ought to be inspired and then try to convince themselves that they are. The expectations are kind of mind-blowing, but we are expected to pick ourselves up and move on. And I do what I can do; I do yoga, I do psychotherapy, I do Zoloft, but I don't do survivor. And with your indulgence, I would like to read from my book to explain why it is that I don't like the word survivor and really rebel against it. When I was doing radio interviews and TV for this book, I have to say that people could not deal with that. It was just so eye-opening. Every single interview I did, I think, mentioned the fact that I don't use that term and opened the phones for questions. And it was amazing. I do not call myself a survivor. This is my personal choice. I know that's probably the word that many of you use to describe yourselves and that's fine by me. I don't want to rain on anybody's parade. I think most people who use that term do so because it makes them feel strong and victorious, but, for me, not so much. For one thing, to the extent that it is possible, I want to resist labeling myself in terms of cancer. I know a fair number of other women who feel exactly the same way. Mainly, it would make me feel a little nervous to call myself a survivor. To me, a survivor is a term for someone who has a) had a serious brush with death and b) escaped it. Both of those conditions have to be met in my definition. By those standards, I can't call myself a survivor. Take part one. I didn't see myself as having an actual brush with death. It was more like death sent me a postcard with the words, "Thinking of you" inscribed on it. It was kind of a spooky reminder that death is out there somewhere, but it was not exactly a brush, per say. I never saw myself as being at death's door and I certainly never thought that death was at my doorstep. And then there's part 2. Let's just say, for argument's sake, that it *was* a brush with death. I can't guarantee that I've escaped it forever. I mean, if you were in a plane crash and you walked away from it unhurt, it can't come back to harm you later, hence, you are a plane crash survivor, most definitely. Now if you have another plane crash, a recurrence if you will, and you walk away from that one, I guess you could say that you are a two-time survivor, but I would suggest that you find some other means of transportation. Breast cancer is not in any way like being in a plane crash. And I'm just not sure I can ever call myself a survivor in the traditional sense of the word. With breast cancer, you can be clean for years, in essence walk away from the crash, and then get it again. That's the thing about breast cancer, if you go five years, your odds are good, but you're never totally in the clear. You can get a recurrence any old time. Or you may be cured of one breast cancer, but get a completely new and unrelated one. Fran Visco, who is the President of the National Breast Cancer Coalition, told the New York Times you're never assured the disease will not come back. The NBCC uses the term, she says, but only because most people accept it. She doesn't like it for herself. To me, the answer to the question, “How do you know if you really are cured of breast cancer?" is when you die of something else. I just can't call myself a breast cancer survivor. I guess that makes me a very odd combination of superstitious and realistic at the same time. The thing is, I don't have a magic answer. At the panel that I moderated, the surgeon who was on the panel was bombarded by questions from women who wanted to know some of the questions that were raised earlier this evening. What symptoms should scare me? Which ones should not? What tests are really important? Which ones are not? Is there anything that I can be screened for? They didn't get great answers. Everyone's case is her own. Your story is your story. There are aspects that you probably have in common with other people, but each of us has a unique pathology and a unique set of decisions to make, and a unique faith. I don't let myself get hung up on other women's stories because they aren't mine. All I can do is live with my own story, laugh as much as absolutely possible and remember that it's been four years and counting.

V. Psychosocial Issues Post-Treatment and the Impact on the Cultural Practices of Jewish Women

Shera Dubitsky, MEd, MA

Shera Dubitsky: Thank you, Shelley, I believe that your remarks resonated with many of the women on tonight's teleconference.

Earlier, I alluded to the emotional challenges facing women post-treatment. The fact that some emotional difficulties don't come until after treatment makes sense to me for several reasons. I believe that we are wired to survive. If your health is compromised, falling apart while undergoing treatment would be too overwhelming. It would be difficult to function. Therefore, once your body is on the road to healing from surgery and or treatment, there's more room to "fall apart emotionally."

Also, once treatment is finished, there is a greater space between doctor appointments, or being monitored by your treatment team. Many women count down the days until treatment is over, yet, not seeing doctors as frequently as they had during treatment generates a breeding ground for fears of recurrence or other worst-case scenarios. There's a comfort zone in knowing that you are being seen daily, or weekly, depending on your treatment. When treatment ends, women worry that their safety net is gone. Another reason for post-treatment emotional difficulties is that there's a pressure to go back to your life as it was before diagnosis. The thought is: All right, treatment is over. Now things will be the same as they used to be. That pressure can come from you, or from family and friends. I believe that once you are diagnosed, your emotional and spiritual DNA have changed forever. Maybe some of you have been able to pick up your lives where you left off pre-diagnosis, but for others, it's important to develop a new normal, a stability in your life.

The new normal will define and re-define itself naturally. If you don't allow this process, you may find yourself experiencing increased stress, anxiety, frustration or resentment. There is a hope, or expectation that once treatment is behind you, cancer will be behind you.

A common side-effect of cancer and cancer treatment is the brain chatter that occurs from diagnosis to post-treatment. How am I going to survive this? I'm worried about my family. Did I make the right treatment decision? What if this recurs?
I'm sure that many of you are over-achievers when it comes to imagining worse-case scenarios. I often think of a volume control knob on the stereo. Sometimes the volume

is up really loud, and sometimes the volume is low and it feels like background noise. There are days when the thoughts are quiet and other days when the thoughts are piercing. I don't believe that you ever truly shut off the volume completely. I think the best that you can shoot for is to learn how to live with the background noise. And many women are able to achieve this.

For some Jewish women, the word survivorship is troubling because of the association of being a survivor from the Holocaust. For other women, the notion of being a survivor seems to stem less from a place of Jewish history and more from a sense of Jewish superstition. There is a certain fear among Jews about tempting fate. Some call it the evil eye, or Ayin Harah, some refer to it as “Al Tiftach Peh le Satan” – “Don't open your mouth to Satan.” Suddenly we have a world of Jewish women emulating Golda from Fiddler on the Roof, who are spitting to keep the evil eye away. Whatever you call it, the premise is this: If I identify myself as a survivor, will some higher power come to deny me that status? Better not to embrace the term, and to transition quietly into survivorship. But that can be difficult to do today, in the age of Races and Walks, celebrations of survivorship, by every major cancer organization. While many women take up the cause and may embrace “survivor”, some Jewish women are fearful of that very term.

For women who have contacted Sharsheret, transitioning beyond breast cancer can bring with it the search for a community consisting of other Jewish women touched by breast cancer. Sharsheret has become a community of sorts for women seeking a place to explore tradition and spirituality within the context of a shared experience. Sharsheret addresses the unique ways in which breast cancer affects the Jewish woman in her life after active treatment.

Using the Mikvah, or ritual bath, can be a time of renewed healing. For some, immersion into the Mikvah waters is a custom associated with marriage that takes on added meaning after surgery and treatment. Using the Mikvah can also be a time to embrace a new tradition that can bring hope for help.

For others submerging in the Mikvah can force a confrontation with body image and sexuality. It can be a trying time, particularly if discussions about intimacy and body have been ignored during the hectic pace of active treatment.

Perhaps some of the most urgent subjects for young Jewish women touched by breast cancer are fertility and parenting. In addition to the personal desire for many young women to biologically parent a child, younger Jewish women often feel the pressure of a community emphasis on family.

For single women surviving breast cancer, issues of fertility can affect potential partnership. For married women, even those with children, the pressures can be just as significant, particularly in those communities where large families are the norm.

For those survivors who remain fertile, the decision whether or not to have children after breast cancer often adds another dimension to the anxiety of life post-treatment, particularly for women who are hormone-receptive positive, who fear that hormones coursing during pregnancy may trigger a recurrence.
Also, women who have tested BRCA positive may have concerns or guilt about passing along the genes to their children.

Finally, fears that get played out over and over again for Jewish women post-active treatment, are the ones that add another dimension to Jewish milestones like Bar and Bat Mitzvahs, and weddings, where many cancer survivors are likely to think: "I hope I live to see this."

These are fears that also weigh heavily during the Jewish holidays, particularly during the new year holidays of Rosh Hashana and Yom Kippur, which trigger serious interception about matters of life and death. At the same time, these Jewish milestones, these Jewish holidays can also be a time for celebration - for affirming and embracing the challenges of survivorship. Through organizations like Sharsheret, Jewish women can embrace those challenges together, in an atmosphere of confidentiality and respect.

I encourage you to call or e-mail Sharsheret for further support on these issues. On Links, our peer supporters are a wonderful resource. These women are further down the road on this journey and have a keen insight into the challenges that many of you may be facing.

VI. Question and Answer Session

Moderated by Shera Dubitsky, MEd, MA

I would like to now open the floor for a brief question-and-answer period. I ask that you keep your questions general and broad enough so that all the participants can benefit from the discussion.
We have questions that came in through e-mail.
Dr. Oratz, maybe you can address this. What is the follow-up protocol for women with triple-negative breast cancers, as it is limited and different, compared with those that are not?
The caller also wanted to know if triple-negative is more common within the Jewish community.

Ruth Oratz: This really gets to a very important issue, and that issue is that not all breast cancers are the same. We now understand that there are many, many different types of breast cancer. The treatment for breast cancer and the follow-up depends not only on the stage at the time of your diagnosis, the size of the tumor and whether or not lymph nodes are involved, but more importantly on the biologic sub-type of cancer that you have. Is it estrogen receptor positive or negative? Is it HER2/neu positive or negative? If it's triple-negative, that means that the estrogen receptor, progesterone receptor and HER2/neu receptor are not present on the cancer cells.

There are many different versions and variations, as you can imagine, of how we put together and mix and match these different molecular characteristics. There are, in fact, other molecular characteristics and histologic characteristics, things that you see on your pathology report that help us predict the risk of recurrence and help us choose your treatment.

Once you're finished with treatment, make decisions about what your follow-up should be. There are different recommendations, to some extent based on the stage of disease, and to a lesser extent on the sub-type of your cancer.

But, as you heard earlier on, the national standard guidelines from the American Society of Clinical Oncology from the NCCN guidelines, do not recommend routine scans. That means we do not recommend pap scans, or bone scans, or x-rays on a routine basis. Each individual patient with her doctor should set up a plan that makes sense for her. In some instances, it might make sense at some point to repeat a scan, particularly if there was a subtle finding. There are some women, who absolutely, positively, must at some point along the way, have a scan just to be able to go to sleep at night. We don't normally like to order tests that aren't "medically required," but there may be lots of definitions of what required means. I can't tell you that there are specific recommendations for the triple-negative or basal-type breast cancer, because right now we don't have a magical test that's going to differentiate a recurrence in the triple-negative cancer from some other type of breast cancer. But based on the stage of disease at presentation, and each individual woman's own circumstances, she should discuss that issue with her own medical oncologist.

In terms of whether or not triple-negative breast cancer is more common in the Jewish population, I don't know of any studies which have looked specifically at that, although there is a slight increase in incidence of triple-negative breast cancers in association with BRCA1 mutation. We know that BRCA1 mutation mutations are more common in the Jewish population than in the non-Jewish population. So, we could probably surmise that there are a higher number of triple-negative breast cancers in Jewish women than in non-Jewish women. But I can't tell you that there's been a study that quantifies that specifically.

Shera Dubitsky: Thank you Dr. Oratz.
Dr. Cigler, a question came in about getting a hard copy of a sample survivorship plan. Is that something Sharsheret can send out to the callers on this teleconference? This caller thinks that it would be a great thing to bring to the doctor in case they don't have them yet. What are your thoughts on that?

Tessa Cigler: There is no absolute prescription to what the survivor plan should look like. There is a sample that's available through the American Society of Clinical

Oncology, on their Web-site. It would be easy to provide Sharsheret with an example of the survivorship plan. The survivorship plan always should include the type of breast cancer, including the receptor status, the estrogen, progesterone and HER2/neu, the stage of the breast cancer, and the treatments that the woman received, including, each chemotherapy agent, as well the doses, the radiation treatment, the surgery treatment, as well as the hormonal treatment, if any. The survivorship plan should include instructions on post-treatment follow-up, including the frequency and timing of mammograms. For some women, MRI's are recommended as screening methods, and that needs to be carefully worked out among the women's physicians.
As for other follow-up tests, there are no strict guidelines for routine tests, like blood tests, or tumor markers, or staging scans to be done. Each specific woman has should have her own plan developed. The survivorship plan should also include how often the woman should follow-up with her oncologist.

Shera Dubitsky: Thank you Dr. Cigler.
We have another question that came in that perhaps you can address. This woman was diagnosed 11 years ago and she can't sleep at night. Her gynecologist said that she needs to live with this. Is this common?

Tessa Cigler: Women can have symptoms for many, many years following their diagnosis. I think before I could say that it is common, I would need to know more of the specifics of this particular caller’s treatments, hormonal status, her age, her menopausal status, what treatment she received. With that said, if she is having trouble sleeping, the overwhelming hope is that a team of medical professionals could come up with something to alleviate her symptoms. And there are certainly options for that.

Shera Dubitsky: We encourage her to go back to the treatment team to explore the options.

Tessa Cigler: Absolutely, to an oncologist and/or primary care physician, and have them speak with her gynecologist.

Ruth Oratz: I think that was an interesting comment she made, that she can't sleep at night. I think the first question we have to ask her is what's keeping her up?
Does she have physical symptoms? Is this something that's psychological? Does she have some other factor that's impairing her sleep, hormonal issues, menopausal symptoms? What is she eating and drinking before she goes to bed at night? I mean there are some practical things that we can address that have to do with sleep. Sleep is really important. But most of us, I would venture to say, probably don't get into bed at 10 or 11 o'clock at night and sleep through the night until 7:00 in the morning. I think if we ask every single person who is on the telephone tonight if she does that on a regular basis, not one of us could answer yes to that question.. There's also some mythology about sleep. Most of us don't sleep through the night every single night of the week. That's probably okay. But if you're really sleepless for whatever reason, and fatigued by it or emotionally fatigued by it, then we have to really dig in and dig down. Sleep is

something that comes up frequently and I think to myself, “how well do I sleep at night?” Well, not so well some nights. We have to also put that issue into perspective.

Shera Dubitsky: Thank you. This one goes to you, Dr. Oratz. Can you talk a bit about how chemo affects bone loss if you don't stay in menopause, and how do you avoid this with weight-bearing exercising?

Ruth Oratz: Bone health is a really important issue for women, whether or not they have breast cancer, whether or not they're getting chemotherapy. As we get older, all of us will see a decrease in our bone mineral density. Loss of bone density is not an illness. It is not a disease, and it does not always require medical treatment. Men will also have a decrease in their bone density as they get older; maybe not to the same extent as women, but they definitely lose bone density. That's a normal part of the aging process. What we are concerned about is if there is either a very rapid change or decrease in the bone density, or if the bone density looks like it's starting to approach a level where the risk of fracture is getting high. Most of us will live through our lives whether or not we've had breast cancer, whether or not we've had treatment, whether or not we even ever measure our bone density and we're not going to break our bones and we're going to be fine. Some women will suffer fractures from osteoporosis. And that's what we want to prevent. It's important to pay attention to bone health and there are things we can do to maintain bone density.

The most important things are probably weight-bearing exercise and adequate amounts of vitamin D, in particular vitamin D3. I stopped measuring vitamin D levels in my patients because everyone is low. Everyone, across the board, we're all deficient in vitamin D. So I think we all should be taking more vitamin D. You need a little bit of sunlight to activate that vitamin D, not so much that you have to worry about getting skin cancer, but a little bit of sunlight.

You need to do weight-bearing exercise. Weight-bearing exercise for the lower extremities can be as simple as walking for 15 or 20 minutes three or four times a week. Don't forget the upper extremities and the spine. That can either be gentle weight lifting or doing other kinds of exercise, like yoga or Pilates, or other kinds of things where you are engaged in using your torso and your upper extremities, as well.

Those are the most important things you can do to maintain bone health. If we see that the bone density is really decreasing, then we may consider medical therapy and there are a number of treatments ranging from oral medications to intravenous ones if you can't tolerate the oral drug.

There's also some data that suggests that for women who have estrogen receptor positive disease, some interventions may help to reduce the risk of recurrence of breast cancer, particularly in the bones. So, it's important to watch bone health.

The effect of chemotherapy on bone density really depends on how much chemo you've had, how old you were when you received the chemotherapy, and again, whether or not you're put into a menopausal state, if that's sustained or not sustained, if it's premature or not premature. It's variable from one patient to the next.

Shera Dubitsky: I want to go back to what you were discussing about rigorous exercise, but on a different topic, namely, lymphedema. This woman has swelling of her breast that started after radiation and it got worse with rigorous exercise. She wanted to know if the two are related. A second question on lymphedema is: If you don't have lymph nodes removed, what are the chances of getting lymphedema?

Ruth Oratz: Let me just back up and say, I was not suggesting rigorous exercise. I said, walk 15 or 20 minutes three times a week, not train for the marathon. Physical exercise doesn't have to be rigorous. You just want to be moving around, have good range of motion, have some decent cardiovascular reserve and so on. If you can do more, that's terrific. But it's not a requirement that everybody start training for the marathon, that's number one. Number two, the breast can develop lymphedema, as well as the arms. It is seen sometimes after radiation therapy, that the breast itself gets swollen. You may even see some dimpling of the skin and that feeling of heaviness in the breast that persists for a long time after radiation therapy. It is possible that if you do a lot of rigorous upper extremity work, you're going to be pushing that lymphatic fluid into the breast, as opposed to draining it away from the breast. It may be that exercise may exacerbate that sense of swelling in the breast. Many medical centers have, as part of their rehab departments or physical therapy departments, special post-breast cancer exercise and physical therapy programs.

There are other ones that are not affiliated with medical centers. Moving on Aerobics for example, is a great program for women who are recovering from cancer and want to start moving. It's actually sort of fun, kind of like a dance aerobics program that is a whole body movement program. If you're having a specific problem with lymphedema, either of the arm or the breast, I would recommend consultation with an expert to really do a careful evaluation and help you to define the appropriate exercise program for you. In terms of the risk of lymphedema, the greatest risk is associated with the more intervention that you do. The more surgery that's done under the arm, the greater the number of lymph nodes that are removed and the higher the dissection goes; and if there is radiation therapy in conjunction with that, the risk of lymphedema is higher. The less intervention there is to disrupt those lymphatic vessels that are draining from the arm, the less the likelihood of lymphedema. I would say, overall, the national statistics in rough estimates are that about 5% of women will develop clinically significant lymphedema.

Probably, more women than that will have a lesser amount of lymphedema that is not really worrisome, but nonetheless, they could still benefit from consultation with someone who's an expert in post-breast cancer physical and occupational therapy.

Shera Dubitsky: Thank you.

Dr. Cigler, we have a couple of questions about Tamoxifen. Does Tamoxifen cause joint pain? Also, can you mention some medications to take for hot flashes while on Tamoxifen?

Tessa Cigler: The issue of joint pain while taking Tamoxifen is a very, very interesting one. There is a lot of evidence to suggest that as estrogen levels decrease as women go into menopause, that in and of itself might trigger some joint pain. In the big studies looking at Tamoxifen versus placebo, an excess of joint pain was not seen in the Tamoxifen group. In fact, women in both groups experienced some amount of joint pain. This is in distinction to the aromatase inhibitors, which have certainly been implicated in causing a lot of joint and muscle pain.

That's an area of active research as to which aromatase inhibitors do cause joint pain. That said, every woman develops her own symptoms and her own side effects to different medications. I wouldn't be surprised to hear of someone having joint pain on Tamoxifen. The hope would be that we could manipulate either the Tamoxifen or use supportive measures to help the joint pain.

Shera Dubitsky: Dr. Cigler, can you talk a little bit more about the chances of getting pregnant after chemo?

Tessa Cigler: Fertility after chemotherapy is really dependent on a lot factors. It's certainly dependent on the age at which you start your chemotherapy, as well as the specific chemotherapy that someone receives. Obviously, the younger you are when you start your chemotherapy, the less likelihood of going into menopause from the treatment. The type of chemotherapy that one receives is also very important.

Shera Dubitsky: Who would they speak to about those different variables?

Tessa Cigler: That is something that should be discussed at the very beginning of treatment, during the first meeting with the medical oncologist. There should be referrals to a reproductive endocrinologist for all young women undergoing chemotherapy - while contemplating undergoing chemotherapy. Often a woman's treatment plan, depending on her specific tumor, involves months of chemotherapy and then years of hormonal therapy. Even if her menstrual cycle continues and the chemotherapy does not put a young woman into early menopause, from the time she is diagnosed until after treatments are complete, several years will have passed. That, in and of itself, will affect a woman's fertility.

Shera Dubitsky: Thank you, Dr. Cigler. You mentioned a document from the Institute of Medicine; where can we get the information and source of this article. Perhaps, you can provide a link for that.

Tessa Cigler: Sure, I'd be happy to send it to you. The Institute of Medicine issued a report called: *From Cancer Patient to Cancer Survivor: Lost in Transition*. I will send you a copy of it.

Shera Dubitsky: If anybody is interested, they can certainly contact us at Sharsheret and we will get you that information.

Dr. Oratz, a question came in about genetics. What is a good resource for accurate genetic data if you test positive for the BRCA2 gene? (I want to mention that we do have a genetic counselor on staff. If you have genetic questions, I urge you to call Sharsheret to speak to our genetic counselor.)

Ruth Oratz: There are many, many resources about this. I think that if a woman has a diagnosis of breast cancer and she's Jewish, particularly if she's young, Sharsheret is a good resource, because focus is very much on our younger patients. Early-age onset and being Jewish and having a diagnosis of breast cancer lead to a higher probability that you might carry a mutation in BRCA1 or BRCA2. You should have a conversation with a genetic counselor and/or a physician who is really experienced and an expert in counseling about helping to estimate the risk of whether or not you would find a mutation in you, and should you consider doing testing. Once you are tested, how do you interpret those test results in light of past family history? These are very complicated issues and usually require more than one conversation. I would really encourage any individual who is interested to meet with a genetic counselor, or with a physician who is really experienced in this, to get information that is relevant to you as an individual.

If you want general reading, there are some very good web-sites, and there's an organization called FORCE, which is specifically dedicated to these issues of risk and genetic risk. They have a lot of good information. Breastcancer.org is a very good general web-based information resource for all kinds of information about breast cancer, and will also link you to other sources.

I think those would be two good places to start if you just want to do some reading on your own. Myriad Genetics, which is the laboratory that actually does the testing, has a web-site and provides some guidelines for who should consider genetic counseling and testing, and how to interpret the results of those tests.

I would really caution people not to try to counsel themselves. Talk to an expert about your own specific situation, your family history. Remember, both sides of the family count, your mother's and your father's family histories are important. Follow up on these concerns with someone directly, one on one.

Shera Dubitsky: Again, I want to emphasize that in Sharsheret's Genetics for Life program, we do have a genetic counselor. She would certainly be a reliable resource for your initial questions regarding genetics.

Dr. Oratz, can you briefly discuss the cutting edge research that we may see soon for women who are post-treatment for breast cancer?

Ruth Oratz: Well, we're continuing to do lots and lots of research. One of the things that we really should emphasize is that in making treatment decisions, if you are eligible for a clinical trial, try to get on it, that's number one. Clinical trials should be a standard of practice. We're doing research and trying to understand how we can minimize using toxic chemotherapy and minimize the side effects related to chemotherapy. We're looking more and more at the molecular mechanisms that drive breast cancer cells to grow, and we're developing new and better targeted therapies, not only against the estrogen receptor and the HER2 receptor. We have drugs now that are looking at the HER1 and HER3 receptors at the DEaF and EGFR receptors and so on.

There's a whole host of target biologic treatments that we are investigating, as well. Even in radiation therapy, we're doing clinical trials; looking at different schedules, different doses, different positions on the table to maximize the benefit and minimize the side effects. And that's true for surgery also, particularly in the area of plastic surgery for our patients who require mastectomies. The plastic surgeons, together with the oncology surgeons, are working on some very exciting new techniques to have better and better reconstruction.

Research is definitely ongoing, active, alive, and has already resulted in a decrease in mortality from breast cancer, which we're now seeing for the first time. That was presented last year at San Antonio. We're all looking forward to going back to Texas in a couple of weeks to hear this year's update on the research results that have accrued from this year's work. Hopefully after San Antonio, we'll have some more information for you.

Shera Dubitsky: That's very encouraging, thank you.

Shelley, a woman wrote that she had read your book. She wanted to give you feedback- that she found your remarks and your book very validating. This woman felt the same way. She didn't want to parade in pink.

We do have a question that asked: What strategies do you use to quell the fears and concerns?

Shelley Lewis: Well, I'm four years out, and I don't think about cancer a lot and then suddenly I'll have some weird symptoms. The older you get, the more things tend to break down anyway, so you just try to keep an even keel and remind yourself that the odds are that a cold is a cold and not a metastasis.

I wish I had great wisdom. I think we all learn to live with a certain level of fear. I do see a shrink; I didn't for years. I couldn't even begin to feel my feelings enough to do that, but I think therapy is really helpful for me. I go to a yoga class that is for women who have had breast cancer, which is great for my head, as well as for my body. I am in a book group that is for women who have had breast cancer- some of them are still in treatment. Though I don't feel that you necessarily need to be around people who've had cancer to be with people who can relate to you. I think intelligent, empathetic people, whether they've had it themselves or not, can relate to you, but I do think there is a certain shorthand when you're with other women who've had the a similar experience, and I think that it is really helpful.

Another thing that keeps me from being afraid, is that I try to make myself as available as possible to women who are newly diagnosed. I never, ever, ever try to give medical advice, but just to hear and talk about experiences. By doing some of that, you hear it a little bit more objectively, so you can translate your own concerns. You can put yourself in the position of that person you're talking to.

VII. Teleconference Conclusion

Closing Remarks

Shera Dubitsky: Thank you. That is very helpful.

As we wrap up this evening, I'd like to thank all the speakers for their wisdom and warmth in discussing the many issues women are facing post-treatment.

Please be sure to complete the evaluation forms you've received in your information packet or online. You're feedback is very, very important to us. And again, I encourage you to reach out to Sharsheret for further support and resources. The phone number is 866-474-2774; or you can email me directly at sdubitsky@sharsheret.org.

I want to thank you all for joining us this evening. The road towards survivorship, however one defines that term, can be at once exciting and terrifying.

Tonight, our speakers have shared their insights into this journey. A journey shared by women affected by breast cancer and their families. We look forward to continuing this important conversation with you all, in the hope that survivorship rates continue to soar in the years ahead.
Good night.

VIII. 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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