

# **Surviving Young Life After Breast Cancer**

**Transcript of the Symposium Presented at  
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New York City  
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**Symposium Presented By:**

**Sharsheret**

**Linking Young Jewish Women in Their Fight Against Breast Cancer**

**Symposium Sponsors:**

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## I. Introduction

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**Rochelle Shoretz:** Thank you for joining Sharsheret at our fourth educational symposium, “Surviving Young: Life After Breast Cancer.” My name is Rochelle Shoretz and I am the Founder and Executive Director of Sharsheret, which is Hebrew for “chain,” a national organization supporting young Jewish women facing breast cancer. 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 for those affected by breast cancer -- survivorship. I want to welcome those who are joining us here in New York as well as those participating via webcast. We have participants from dozens of states across the country, and many more are certain to join us as the webcast remains available online after tonight’s event.

I would like to begin by thanking those who have made this important event possible. A generous grant from UJA-Federation of New York enabled Sharsheret to bring us all together this evening. UJA-Federation helped Sharsheret commit to ensuring the broadest access possible, and their support has given this New York event a truly national audience. I’d like to recognize Elise Slobodin of UJA’s Caring Commission who is with us this evening. Elise, could you stand up, please? There she is. Thank you to our symposium supporters -- Weill Medical College of Cornell University, who opened their doors to Sharsheret, The Center for Reproductive Medicine and Infertility, and Fertile Hope, a national nonprofit organization dedicated to providing reproductive information, support and hope to cancer patients whose medical treatments present the risks of infertility. And finally, Sharsheret is privileged to present tonight’s symposium in partnership with the Lance Armstrong Foundation, an organization dedicated to providing the practical information and tools cancer survivors need to live strong. Sharsheret’s staff and volunteers have worked tirelessly – and in particular, I’d like to recognize Elana Silber, our Program Coordinator, who coordinated this remarkable event and so many others.

When I was diagnosed with breast cancer four years ago, I became slightly obsessed with the calendar. I counted the weeks between surgery and treatment, until that last chemotherapy appointment, and then each day of radiation. Still today, I find myself calculating how many more months, years, until I no longer have to renew my prescription for Tamoxifen. But though my efforts have been, largely, to put cancer behind me, I am learning, slowly, that it is much more important that I learn to walk comfortably beside cancer.

Cancer survivorship has become a pressing subject in the health care community. As men and women live longer lives beyond breast cancer, organizations like the Lance Armstrong Foundation and the National Cancer Institute have begun to highlight the importance of educating cancer patients

about life as a cancer survivor. The term “survivor,” though, itself raises a number of questions. When exactly are we considered “survivors?” And how to reconcile the term “survivor” with the persistent voice in your head that often whispers, “It’s going to come back. It’s just a matter of time.”

Over the past three years, many of the women who have called Sharsheret for support at the earliest stages of diagnosis have called back for support once it was all seemingly over. Many of you may have the same questions that they’ve asked us -- How often do I need to be seen by a doctor, and which ones? What form of breast cancer screening is recommended for young women who have already been diagnosed with breast cancer? How do I cope with the fear that cancer will strike again? What is the most effective way to stay on top of emerging cancer research? And, finally, what nutrition and exercise guidelines are available to me after treatment?

Our speakers tonight have generously contributed their time to address these important questions and more. We will hear brief presentations from each speaker and then, after a break, we will take questions from our audience.

But before we begin, I would like to highlight Sharsheret as an available and valuable resource for those of you participating this evening. Sharsheret was founded in 2001 to support young Jewish women facing breast cancer. We now offer three core programs -- Our Link Program connects women across the country in one-to-one conversations with peer supporters who share the same backgrounds and concerns. Sharsheret’s Quality of Life Programs are designed to enhance the quality of life for younger women living with breast cancer with initiatives like the Busy Box for parents of young children and Best Face Forward to address the cosmetic side effects of treatment. And finally, our Education and Outreach Program educates women, their families, communities, and health care professionals about the issues facing women with breast cancer with symposia like this one. In just three years, we have received more than 3,500 phone calls from women affected by breast cancer, their family members, and healthcare professionals.

And during these past 3 years, the subject of survivorship has become increasingly more important in the cancer community and in our Sharsheret community. Our goal tonight is to answer some of the critical questions you have brought to our attention, raise new ones, and generate discussion about the ways in which we can enhance the quality of life for those living beyond breast cancer. This is the first of what is certain to be an ongoing conversation, and we encourage you to stay involved as the Sharsheret, the chain, continues to grow in the years ahead.

It is now my pleasure to introduce Dr. Ruth Oratz. Dr. Oratz, a member of Sharsheret’s Medical Advisory Board, is an Associate Professor of Clinical

Medicine at the New York University School of Medicine and an oncologist specializing in breast diseases in Colorado. She will start us off this evening by addressing a question she must field often as an oncologist -- How do we stay on top of emerging cancer research once active treatment ends? Please join me in welcoming Dr. Ruth Oratz.

## II. Staying Current On Emerging Cancer Research

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**Dr. Ruth Oratz:** Thank you, Rochelle. It's a pleasure to be back in this auditorium where we've had symposia before and to be in my hometown.

Staying current with cancer research is an enormous job. It's my job as a medical oncologist to stay on top of what's happening in clinical trials, and also to stay a little bit ahead of the curve -- "What's in the pipeline?" as we say in the business. What I thought I would do is share with you tonight some of the new treatment modalities that are really on the cusp. A lot of these treatments are still in the experimental phase, but many of them are going to become more and more important for active therapy and, hopefully, for prevention in the future.

Usually, what we see as we're looking at new therapeutic modalities is that they're tested first in the setting of advanced disease, and we get an idea of whether or not these treatments are active and, if they are, we push them into the adjuvant setting, which is for the newly diagnosed patients, and, ultimately, some of these treatments that I'll talk about tonight may have a role in prevention.

I'm going to give you a biology lesson and a quick overview of some of the new treatment modalities and research projects that are going on around the country, and then you'll hear from our other speakers about some of the other aspects of coping with breast cancer after diagnosis and treatment.

I'm not going to talk a lot about imaging. Dr. Kolb is here and is an expert in breast imaging, but we certainly have seen many advances in breast imaging with digital mammography, the use of MRI in certain circumstances, and ultrasound as some other techniques to be used in conjunction with standard mammography and self-examination for follow-up and for diagnosis. And, after a woman has had a diagnosis of breast cancer, she is at increased risk not only for recurrence of that breast cancer but of a second or new primary breast cancer in the opposite breast or even in the same breast, so it is very important that breast imaging and follow-up be part of continued surveillance.

Let me share with you now what I think is the 21st Century breakthrough in breast cancer. This is what we've been waiting for. Genomics refers to using and understanding the gene expression profile -- that is, the DNA -- that's in the cancer cell to understand the biology of the cancer cell for diagnosis, for prognosis, and ultimately for determining therapy. This is not the DNA that we inherit from our parents. These are not the genes that are passed down from one generation to the next. Rather, we're talking about the DNA that's in the malignant cells. A malignant breast cancer cell was once a normal, healthy cell. Something happened to it. The DNA in that cell is damaged in some way, and

that damage controls the malignant phenotype on the cell -- makes that cell into a cancer cell. We call that transformation.

Now, you all are familiar with the BRCA mutations. We've talked a lot about this in Sharsheret and you know about that in other situations. That's an example of damaged DNA that is passed from one generation to the next, but there are many, many other ways that the DNA in the cell can be affected, and as those DNA changes occur, the cell is transformed from a benign normal cell into a malignant cell. What we can do now is study the genes, the DNA, in the cancer cells, and by understanding which genes are present and in which balance, we can understand and predict the behavior of those cancer cells.

Let me give you an example of something that you might be familiar with, the estrogen receptor. You know that we often talk about whether or not a breast cancer is estrogen receptor-positive or negative. The estrogen receptor is a protein that's on the outside surface of the cell. That protein is manufactured only if there's a gene inside the cell that says "make the estrogen receptor." The DNA is the code. The gene is the code for the protein. So we can measure the amount of estrogen receptor on the outside of the cell, but even better, we can go inside the cell and see if the gene for the estrogen receptor is present.

Many of you have heard of HER-2/neu, which is another protein that's on the surface of the cell, and in about a third of breast cancers it's over expressed -- that means there is a lot of it on the surface. We can measure the amount of protein on the surface of the cell, but even better is if we can go inside the cell and look at the number of copies of the gene -- we use a test called "FISH" in order to do that -- and that is a much more accurate, quantitative, reproducible, and reliable way of knowing whether or not that HER-2/neu is present in that cancer cell, and, if it is, we can target that therapy. We target the estrogen receptor with medicines like Tamoxifen or the Aromatase Inhibitors or other hormonal therapies. We target HER-2/neu with a monoclonal antibody called Trastuzumab or Herceptin. These are two examples of targeted therapy based on whether the protein is present but, ultimately, on whether the DNA, the gene that codes for that protein, is present in the cancer cell.

That's what genomics is, and we now have available to us an array of technology that can look at many of these genes inside the cancer cell and give us information about prognosis and, more importantly, response to therapy. And, in fact, there is a very new test called Oncotype DX, which has just been approved and is on the market for women with early-stage breast cancer -- estrogen receptor-positive/lymph node-negative breast cancer -- but we'll soon see these kinds of tests for all the other subtypes of breast cancer. This test measures 16 cancer-related genes in the breast cancer tissue.

If a woman has a biopsy or surgery, we can send the tissue off to the laboratory, and then if DNA is measured and we get information, that is very, very helpful to me as a medical oncologist in talking to my patient about her prognosis, because the balance of these genes and their behavior tells me what the molecular, what the biologic, characteristics are of the cancer cell and helps me decide on therapy. Is this the kind of cancer that really needs to be treated with chemotherapy or is this the kind of cancer that can be treated with hormonal therapy or other targeted biologic therapies? This is what we've been waiting for. We have been waiting to have this technology that until now has only been in the laboratory to finally come into the clinics where we can make decisions that are rational and targeted and personalized for each individual patient based on the specific biology of the cancer cell growing in the tumor that came out of her breast.

That's what genomics is, so where does that bring us? Well, in adjuvant therapy, which is the treatment of early-stage disease, we already have completed most of our clinical trials asking the question of, "Should we be using Herceptin to prevent recurrences?" Until now, that has been the only treatment for advanced disease. We should be getting the data for these trials within the next year or two.

We're also looking in the adjuvant setting at new combinations of chemotherapy. We want to confirm whether giving treatment in this dose-dense fashion -- that means compressing the treatment into a faster schedule -- and using new agents that may have new delivery systems that perhaps may be less toxic, and maybe even looking at changing the drugs altogether that we use in our chemotherapy regimens. Hormonal therapy, of course, is a mainstay of treatment because at least half, if not more than half, of breast cancers will be estrogen receptor-positive, that is, will have those hormone receptors. And the big question for young women is, "Are there alternatives to Tamoxifen alone?" Tamoxifen is still the gold standard for premenopausal women who have ER-positive disease, but is there something better? This is a clinical trial, the SOFT trial, which is going on now around the country. We're hoping to accrue several thousand young women who have hormone receptor-positive early-stage breast cancer, and we're asking the question of whether adding ovarian suppression to Tamoxifen is better than giving Tamoxifen alone, and by "ovarian suppression" we mean either removing the ovaries surgically -- in Europe they sometimes irradiate the ovaries, although we don't tend to do that so often in this country -- or using drugs, medicines that result in the equivalent of ovarian suppression. This is a large, randomized clinical trial which is asking a very, very important question in terms of the hope of reducing the risk of relapse for ER-positive disease.

This cartoon is here to just remind you of the biology. Here's the membrane of the cancer cell, and these are the proteins I was talking about that stick up, receptors, that are on the surface. This is the HER-2 molecule. We know there

are several others -- there are 1, 3, and 4 -- and there are all these other compounds up here that regulate what goes on in the cancer cells. These receptors on the surface get a message, then through this enzyme called tyrosine kinase, that message is delivered inside the cell, and the message may either tell the cell to proliferate, to grow, or it may turn off the cell. It may tell the cell, "Stop growing. Go away." We are now trying to take advantage of these molecular characteristics of the tumor cell to target therapy.

Let me show you some of those. Now, the tyrosine kinase inhibitors -- remember I showed you here that tyrosine kinase molecule? We can block the signal coming out of that molecule with all of these drugs, and they're all being tested now in advanced stages of breast cancer and, hopefully, will play a role in earlier stages. IRESSA may be familiar to some of you as a drug that's been used for treating lung cancer, as has Tarceva. Both of these agents now are being tested in breast cancer, sometimes in combination with chemotherapy or hormonal agents, sometimes alone.

This is a new agent, Lapatinib, which is showing a lot of promise, and you'll see clinical trials combining Lapatinib with either hormonal therapy or chemotherapy - - very exciting and promising in direction.

The monoclonal antibodies -- Herceptin is the one we're familiar with. It's on the market, and these are two other antibodies that are targeted to other proteins that may have a role, again, in earlier stage disease if we show activity in advanced disease.

IRESSA targets that tyrosine kinase, and you'll see this on the Web and in the handout, so I'm not going to go through the details of all of these agents, but I'm just providing you here with an overview of each one of the drugs and where it's at right now in the treatment phase, and these are the monoclonal antibodies.

Finally, I would like to come to prevention and mention that we have just completed accrual to the STAR trial, which is a comparison of Tamoxifen and Raloxifene, or Evista, and we'll soon have information about this in postmenopausal women.

We're still working on genetics, so we want to understand, as I said, the genes inside the cancer cell. And we're still working on more research to understand about the genes that we do inherit from our parents, which may, in fact, predispose [us] to an increased susceptibility of breast cancer. We are learning that there are variants in the BRCA mutations, and we're learning, in fact, that there may be some other genes involved.

Finally, as we work on bringing these new treatments to the clinics, we're also trying to do our treatment in a way that's less toxic, so that your quality of life

during therapy and after therapy is improved. During treatment, of course, we want to make sure that people don't feel sick, we want to prevent problems with infections or anemia, and we want to look at some of the long-term side effects, not only of the illness but of the treatment -- the effect of chemotherapy on cognitive functions, so-called "chemo-brain," certainly, effects on fertility and sexuality, which are very, very important long-term effects, and you'll hear more about those a little bit later this evening. I want to emphasize that there's an enormous amount of research going on. This research is taking place in the laboratories. The more we understand about the molecular biology of breast cancer and bring those data into the clinics -- [the more we can use that research] first in advanced disease, then in the adjuvant setting, and ultimately, hopefully, in prevention. Keep your eyes and ears opened for new clinical trials. I would always encourage you to participate in clinical trials if they're available to you. And there is a lot more to come in this pipeline. It's very exciting and promising. Thank you.

**Rochelle Shoretz:** Thank you, Dr. Oratz. It is always a pleasure to have you back in New York with us, and your remarks helped set the stage for the remainder of our discussion tonight.

You will all have an opportunity to submit questions for Dr. Oratz during the Question-and-Answer Session at the end of the presentations this evening. In the meanwhile, I encourage you to write down any questions you may have on the index cards we have distributed in your packets and submit them to the volunteers who will circulate later on.

Dr. Thomas Kolb has been a member of Sharsheret's Medical Advisory Board since the organization's founding. He is a radiologist in private practice in New York City specializing in the detection and diagnosis of breast cancer predominantly in premenopausal women. Tonight, Dr. Kolb will address follow-up care for young women post-treatment -- how often should we be screened, and how? Please join me in welcoming Dr. Thomas Kolb.

### III. Follow-up Care Post-Treatment

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**Dr. Thomas Kolb:** Thank you very much, Rochelle, and thank you, Sharsheret, for having me tonight. Those of you who know me, know that being given 15 minutes of time to tell you what I want to tell you is a difficult process. But we're going to go through a lot of information now, and we're going to talk about how best to optimize breast cancer detection in young and high-risk women, and, of course, those women who have already been diagnosed with breast cancer certainly fall into the category of high-risk.

First of all, we're going to start with the basics and what tools we have to diagnose breast cancer. We, of course, have physical examination, and for the purpose of this talk, we're going to use physical examination synonymously with clinical breast examination -- that is, a physician performing physical examination as opposed to breast self-examination. There is, of course, mammography. We're now in the digital age, although the advantages of digital mammography have yet to be shown. In the near future, they will be shown to be advantageous over and above non-digital or analog mammography. There is ultrasound, which we'll have something to say about as well, and then there's MRI. Here I highlight "other," because almost there's not a day that goes by when someone comes into my office and says to me, "Well, what about this new technique that I've heard about or read about on the Channel 7 News, and why aren't we doing it more often?" The bottom line is the only modalities that have been studied, not that even have been found to be advantageous or beneficial, but have been studied are these four, to some degree. When you look to other technologies such as infrared, such as electric potential, and so on, or laser mammography, there is no scientific validity to that at all. And so we're going to discuss the four modalities that I've described here.

Now, we're going to talk, of course, about the basics -- how good are these tests? And then the best scheme to screen -- what's the best way to detect breast cancer in its earliest stage?

Now, let's first talk about physical examination for a minute, and you should understand that there has never been a study that describes a benefit to doing clinical breast examination or self-breast examination for that point. These screening clinics that exist are for high-risk surveillance patients that have physical examination frequently. There is very little scientific basis to show that there's a benefit to doing all that physical examination, and that's important to understand so that you should not be misled in a false sense of security. Clinical breast examination, however, is being recommended by the American Cancer Society annually in adulthood and more frequently, whatever that means, in high-risk women. It may be every three months. It may be every six months.

Mammography -- annually from the age of 40 and up, but in high-risk populations we start earlier. We start approximately 10 to 15 years prior to the age of the closest primary relative that is diagnosed with breast cancer or from the time of diagnosis in very young women, but we never do mammography more than annually. There are x-rays involved with mammography, and while there is a theoretical risk that has never been shown to be a practical risk for developing breast cancer from the test, we still never, ever do mammography more frequently than annually.

The American Cancer Society has stated, and many medical bodies have stated, that the accuracy of mammography, of screening mammography, is approximately 85 percent. But that really doesn't tell the story, because that's only if you take large numbers. If you're taking a target population of women and don't subdivide them, look at them as a whole, mammography finds approximately 80 -- 78 percent is what we found -- but approximately 78 to 85 percent of breast cancer. As I said, that doesn't tell the whole story. There is a big difference in screening mammography and subdividing within different age groups. We know that the overall mortality reduction, and that is how frequently mammography causes extension of life, is very different in different age groups. There doesn't seem to be as much of an impact on younger aged women by screening mammography as there are in older women. We know that. We know that's a fact. Now there are two reasons that you can postulate as to why this is. It could be that younger women are generally premenopausal and generally have denser breasts, and we're going to talk about breast density in a moment. And so that's a way of detection because the Achilles heel of the mammogram is a dense breast, and we're going to discuss that. Or it could be that younger women have more aggressive tumors, and so even if you find these tumors, it may not be as helpful in younger women as in older women. Now both of these aspects aren't in play here, but as I'll show you, there is a way to detect cancers in younger women -- or there is a way of evaluating the detection of cancers in younger women that give them the same survival prognosis as in older women even though those cancers are not being detected, and we're going to talk about how we can detect those cancers at a small size.

Why has mammography failed to detect breast cancer? Well, I've just told you about breast density. In one of our studies we showed that breast density is the single most statistically significant important factor, which describes the mammogram's ability to find or to miss breast cancer. So let's talk about dense breasts. Who has dense breasts? It turns out that two-thirds of all premenopausal women have breasts that are dense enough that cancers will be missed commonly on a mammogram -- two-thirds of all premenopausal women. About half of all women who are postmenopausal that are taking hormone replacement therapy and about a quarter of all postmenopausal women not taking hormone replacement therapy have dense breasts. We're going to look at

this population here of premenopausal women in that that is the group that Sharsheret is most interested in and deals with.

Now, dense breasts -- how do you know whether a woman has a dense breast or not? How do you know if you have a dense breast or not? The only way for you to know is by the mammographic appearance. You cannot tell whether breasts are dense or not dense by physical examination or by inspection. A large, pendulous breast and a large, pendulous, soft breast can be dense. A small, firm breast may be fatty. Density only refers to the absence of fat. That's what dense means. The breast is composed of fat, glandular tissue, and fibrous tissue that holds it all together. The glandular and fibrous tissue is called "fibroglandular." It's the machinery that makes milk when necessary, all the ducts that come to the nipple. And then there's the rest of the breast which is fat. Some women have breasts that have a lot of fat, and those are fatty breasts which would be the opposite of being dense, and some women have very little fat in their breasts and those are women that have dense breasts as I'll show you.

The ability to breast feed, the ability to function, has nothing to do with breast density. The only reason breast density is important is because it limits the mammogram. In fact, we've known that breast density is very important to diagnosing breast cancer because back in 1992 the American College of Radiology started grading breast density. Grade 1 -- the breast is almost entirely fat, Grade 2 -- there is some fibroglandular density that could obscure a lesion, 3 -- some density that may lower the sensitivity, and 4 -- extremely dense which lowers [the sensitivity]. The problem is even though they described this grading system, they didn't quantify it. They didn't put any numbers. In other words, they didn't tell us how often mammograms fail in denser breasts as opposed to fatty breasts, and one of our studies did do that and I'll show you the data.

In fact, it's right here. This is a woman with fatty breasts and this is a category here of a woman with Grade 4 dense breasts. And you'll see that the sensitivity of the mammogram in women with fatty breasts is 98 percent. Only 2 percent of cancer is missed mammographically in women who have fatty breasts, but in women with dense breasts, more than half of breast cancer is not detected. This is a picture here of a woman with a dense breast. This is a mammogram, and it's generally a dark picture -- certainly, much darker than the one next to it, and you'll see a little white patch right there, and that little white patch is a 5 millimeter, that's half a centimeter, that's one-fifth of an inch cancer sitting in the breast. This is a woman here, a different woman, and her mammogram is all white, and this is a woman who has a dense breast. Fat is dark. Dense is white, but cancers are white. So you can see how a small cancer like this could be hidden in a dense breast like this. It's almost like trying to find a snowball in a blizzard. That's why mammograms miss breast cancers in women with dense breasts, and the only way you know that you have a dense breast is by having a mammogram and looking at it or having a radiologist look at it and relaying that

information, because that information is now very important because you should be treated differently, as I'll show you and tell you, whether you have a fatty breast or a dense breast.

On ultrasound, for example, cancers are dark, but the dense breast tissue remains white. So it's much easier to find a breast cancer on ultrasound in women who have dense breasts than it is mammographically.

This was given to me by a patient of mine. This is Where's Waldo in the shape of breasts, for those of you who have kids, and that's what we're trying to do. We're trying to find breast cancer in a very busy breast that's very dense, and if you look very closely, you can find what you need to find early and accurately.

Now let's go back. Why is there a difference in screening mammography and finding cancers in young women versus older women? This is a slide from Dr. Lazlo Tabar, one of the foremost authorities in breast imaging and cancer detection, and this shows here, tumor size here, and this is age groups, 40 to 49, 50 to 59 and so on, and the grade of the tumor, Grade 3 is much worse than Grade 1. And you'll see that once we hit 15 mm, a little bit more than half of all cancers are now Grade 3, which is the worst prognosis in a lower grade. If you look at those tumors, 15 mm, 15 to 19 mm, in older women, only 31 percent of them are Grade 3. So something starts happening as tumors increase in size in younger women much more quickly than in older women. These tumors de-differentiate. Size is important. Finding a smaller cancer in a younger woman is much more important than finding a smaller cancer in an older woman.

In fact, look at the data. From the best and only studies that compare, women of different age groups and stages of tumors, you will see that in women who are less than 40 or 41 to 50, the 5-year survival for Stage I breast cancer is equivalent to older women. So Stage I disease is equivalent. Younger women versus older women, there is the same survival prognosis. But in higher stage tumors that does not hold. It's important for us to find cancers that are small and early stage, Stages 0 and I, and that's the job of a radiologist.

We're going to talk about what you can do in women with dense breasts. Well, there are a couple of things you can do. One thing you can do is screening breast ultrasounds, and I've spent some of my research time on and published on, and this is me when I was much younger and had more hair giving a screening breast ultrasound as you can all see, and this is the results of our study.

Let's highlight a couple things.

The results of our study -- if you added ultrasound to mammography in women with dense breasts, you would find 44 percent more cancer than if you didn't add

ultrasound and only did mammography. These cancers, 90 percent of them are Stages 0-I. That's fantastic. The cancers that were found were found more than twice more often than those that were palpable, and much, much smaller in size than those found in physical examination.

Now, you can't really read it, but this here is if you would substitute, if you would add on ultrasound instead of physical examination, you would find 91 percent of all cancers in women with dense breasts. This is conventional. This is what we do now, mammography and physical exam -- Stage I breast, fatty breast to dense breast. But if you would substitute ultrasound for physical examination, this is what you would find.

When we talk about high-risk screening clinics that do physical examination very frequently, is it better to do frequent physical examinations or add on an ultrasound six months in between mammograms? There is a multi-institutional study that's now ongoing. It has been going on for a year now where 3,000 women have been screened and there will be results within a year.

Another way we can find breast cancer in women with dense breasts is breast MRI, and these are just a couple of examples of breast MRI, which we'll gloss over, because we'll talk about here -- this category here is if we do mammography and a physical examination and ultrasound. This is mammography, physical examination, and MRI. Instead of ultrasound, you'll find 6 percent more cancer on top of the 44 percent we've already found on ultrasound. I'm going to sum this up to you in 1 minute by telling you that there are issues with MRI that you should know. First of all, if you're going to have an MRI, to me the most important thing is that that institution that does the MRI must have biopsy capabilities. That's the only thing I'm going to verbalize to you right now. Because if it does not have biopsy capability and you have found an abnormality on the MRI that is not seen on physical examination or mammography or ultrasound, then what do you do? Do you tear your hair out? How do you get to it? Not very many facilities, at all, have biopsy capability when they do an MRI, and I will tell you that's one of the things you should be looking for if you were to have an MRI.

What's coming in the future? We're going to fuse mammography and ultrasound together. We'll have a machine that looks like this that will do the mammogram and a card in ultrasound data at the same time so we'll be able to achieve these results much more quickly. Here is a picture of what it will look like -- a mammogram with the ultrasound data showing just a simple cyst. We won't have to call patients back. We won't have to rescan them and so on. The future of ultrasound-guided biopsy is huge because we're going to take out much larger samples from very small incisions, much more advanced than core biopsies that are available now. There are going to be big changes coming just in the next couple of years.

I want to move on. What have we learned? Younger women are more likely to have denser breasts, which makes mammography less capable in finding their tumors. Tumors are more aggressive at smaller sizes in younger women, so it's critical to detect these cancers at a small size and early stage. Mammography finds 48 percent -- only 48 percent of cancer in women with the densest breasts. Screening ultrasound will find an additional 44 percent, and MRI will find on top of that an additional 6 to 8 percent. Yes, if you jump to the MRI, you will find the additional 15 percent that is missed by mammography as well. Physical examination on its own finds very, very little breast cancer.

What do I think the best screening for breast cancer is if you have a dense breast? Well, if you're high-risk, on day one of the year of the cycle of screening, I would do mammography and physical examination. If you're dense, I would certainly add an ultrasound at that time, because you'll be missing more than half of breast cancer if you have a dense breast. Six months later, I would add another diagnostic imaging test. These have not been proven to show benefit, but there is a lot of data in the literature now, and there is no question that it can find large numbers of cancers of various small sizes. You would add either a second-screening ultrasound or an MRI scan.

Thank you very much. I have way taken my time and I appreciate your attention.

**Rochelle Shoretz:** Thank you, Dr. Kolb. I was particularly interested in the picture of that new mammography machine and have just one question for you, although it's not q-and-a time yet. Is it still going to hurt so much, that new machine? Thank you, Dr. Kolb. I know that your research will become increasingly important to young women in the years ahead. And, again, we'll all have an opportunity to submit questions to our panelists during the Question-and-Answer Session later on this evening.

Three years ago we had the privilege of welcoming our next speaker, Dr. Kutluk Oktay, to Sharsheret's first medical symposium, "Fertility After Breast Cancer." You can find a transcript of that symposium on our website, [www.sharsheret.org](http://www.sharsheret.org). The impact of breast cancer on one's ability to biologically parent a child has been one of the most urgent questions for women phoning Sharsheret for support. Dr. Oktay is an Associate Professor of Obstetrics and Gynecology right here at the Weill Medical College of Cornell University and Associate Attending Physician in Obstetrics and Gynecology at Presbyterian-New York Hospital.

As he has another engagement this evening, Dr. Oktay will take questions immediately following his presentation. Therefore, please jot down your questions on the index cards we have circulated, and we will collect them for Dr. Oktay just as soon as he completes his remarks. Please join me in welcoming Dr. Kutluk Oktay.

#### IV. Fertility Options Following Cancer Treatment

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**Dr. Kutluk Oktay:** First of all, I would like to thank all of you for coming to listen to me again after three years. I'm going to focus on the options following breast cancer treatment regarding fertility issues.

What I want to do here is, first of all, discuss with you the main question of how much chemotherapy that you might have received for your breast cancer could affect your fertility, and then move on to the question of how safe is it to perform in vitro fertilization or fertility treatments after the diagnosis of breast cancer, and then, finally, discuss a few things about the safety of pregnancy after breast cancer. These are three major issues concerning young women with breast cancer.

It has been estimated that there will be about 211,000 women diagnosed with breast cancer this year in the United States alone. In general, about a quarter of these women are in premenopausal ages, but about 15 percent or so are in the ages of child-bearing age. That still amounts to a significant number of women. In most of these cases, an adjuvant chemotherapy protocol will be used to treat cancer, and most of these treatment regimens will result in some kind of damage to ovarian reserve, which means early menopause and early infertility.

How much damage can major chemotherapy regimens cause? One of the major regimens, which is probably less commonly used now, CMF, based on the literature, caused amenorrhea. That means no more periods in 20 to 100 percent of patients treated, for an average of about 68 percent. On the other hand, the more recent protocols that involve anthracycline-based protocols, that seemed to have less of an effect. For example, the protocol that involved Adriamycin and Cytosine is associated with about a 34 percent chance of ovarian failure as determined by periods stopping after chemotherapy. With the recent addition of Taxol drugs, Taxanes, Taxol or Taxotere, perhaps there is a change in these numbers. There is controversial information regarding that. But when we look at how much the additional of this T-drug made a difference in our patient population, we nearly see a doubling of the number of women who lost their periods.

The final piece of information I'm going to give you here is that many of you might have received chemotherapy and not necessarily stopped menstruating, but that does not mean that no damage is done. Sometimes you are given false reassurance and you might end up taking your time because of that. But, regardless of what happens with the periods, if you receive the C-drug especially, the damage has been done. What that means is that menopausal age is now moved forward. Perhaps you're going to be experiencing all the problems that an average woman experiences around her late 40's and maybe you're in your

30's or late 30's, and we deal with a lot of patients as such. What that means is that you need to hurry up if you're going to build your family. You don't have as much time. All these studies use menstrual period as a sign of something happening, but that's the last thing to go. So before menstruation stops, a lot of times for 5 or 10 years women are infertile.

The second part is when you have infertility and you have a history of breast cancer is there a relatively safe way of treating you because there is a concern that the high levels of estrogen may take away your cancer, whether it's right or wrong. In the past 4 or 5 years, we've developed certain strategies. They're mainly geared towards women who want to preserve their embryos or eggs prior to chemotherapy, but we've used these approaches in women who had a history of breast cancer and wanted to use fertility drugs but wanted to feel safer.

One of the approaches is using Tamoxifen as a fertility drug. As a matter of fact, it was originally invented as a post-coital contraceptive and then it was found out that it is a good ovarian stimulator. It wasn't until later it became an anticancer drug. We use this drug to stimulate certain patients with breast cancer history to do in vitro fertilization, and these are some examples of pregnancies we had. These are early data, but we have several women with a set of twins and several single pregnancies in this population.

Another protocol that we developed -- as a matter of fact, this paper is being published today in Journal of Clinical Oncology. Again, the focus of that paper, "Preserving Fertility by Freezing Embryos," by using the same protocol we, again, treated women with breast cancer history. We used letrozole, again, another emerging breast cancer drug, along with fertility drugs so that when we stimulate these women their estrogen levels stay low, and with that we have had several pregnancies, and one patient is about to deliver probably in the next few days.

These are all study protocols that we are still not certain that they are making any difference with that, but looking at what happened with those women who froze their embryos with one of these protocols, and they are shown here in this broken line. And when we compare them to a similar woman who did not have in vitro fertilization and we ask the question whether their cancer recurrence rates are increased with IVF treatment, we do not find any difference in cancer recurrence with this relatively short follow-up and a small number of patients. At the early stages of this work, we think that we may have a safer way of doing in vitro, especially for a woman who wants to preserve embryos or eggs, but we're also investigating whether we can use this for a woman with a history of breast cancer who is suffering from infertility.

And, finally, the most important question is pregnancy after breast cancer. What are the concerns? The concerns are if you are pregnant, maybe your diagnosis

will be delayed. If you are pregnant, maybe your treatment will be delayed, and maybe the hormones of pregnancy will promote cancer recurrence, and some people concerned about the psychological issues. Cancer may return and you're caring for a small baby.

Now, let's look at what happens in a normal hormonal cycle. In a normal hormonal cycle we have two major hormones -- one is the estrogen hormone, which peaks in the first half of your cycle, if you have a 4-week cycle, in the first 2 weeks, and the progesterone hormone that peaks in the second half of your cycle. And in pregnancy, now in that graph, the scale I show these 1,000 times less than this. In your normal cycle your hormones would be somewhere here and, in pregnancy, your estrogen hormone goes up many times. Your regular hormonal levels when you're cycling are here, and then the pregnancy related estrogen levels are here. That's the number one concern. If you have that much estrogen and if your cancer is estrogen sensitive, will that stimulate cancer?

On the other hand, progesterone goes up too. Again, your normal progesterone would be somewhere here, but with pregnancy that goes up, too. There is actually a mixture of hormones going up. It's not just estrogen going up, and we really don't understand the mixture effect of all these hormones on your breast cancer. It doesn't necessarily automatically mean that you will be at risk, because there are all these other hormones that are going to be canceling each other out. In the end, you may not be necessarily at risk by getting pregnant.

Let's look at the studies. They divide these studies into two -- one is population based, or you look at your own population and try to determine the risk of cancer recurrence after pregnancy by comparing them to control women with breast cancer who didn't get pregnant. Let's look at the 4 major studies -- the common theme is that the risk of developing cancer because of pregnancy or recurrence because of pregnancy does not change in any of these studies, and some of the studies are actually suggesting it decreased cancer recurrence. Was this relatively significant? If the number is less than 1 that means it's reduced, and if it's more than 1 that means it has increased. So if you look at it and if it's closer to number 1, that means there is no effect. So, as we can see, 4 studies show no effect, and there is 1 study that actually shows that women who conceived had less number of recurrences.

And the same is true for studies looking at a selective group of patients, non-population based, and there are more of those studies, and some of them follow patients for up to 10 years, and the same picture emerges here -- either no increase, or, as you see in this study -- remember I showed you this slide from my study, the survival curve here -- the dotted line shows the patients who conceived after breast cancer and then the straight line is the controls. What we see here is actually at the end of 10 years there are more women who survive 10 years if they conceived than those who did not conceive.

But there are certain weaknesses of these kinds of data. First of all, people cite healthy mother effects --that means only women who are really healthy attempt pregnancy. And so these numbers, if you look at the numbers, it's important that maybe that makes up about 10 percent of the expected number of attempts, even though this probably doesn't factor in the effects of chemotherapy on fertility. Obviously, we cannot design a randomized study where we tell a woman, "You get pregnant. You don't get pregnant. We double-blind randomize." That's not possible, so we're never going to have that kind of data, but my general sense is that we don't have sort of the major impact from pregnancy in most cases.

But then when is it safe to get pregnant? Can you just get pregnant, attempt pregnancy 2 months after you get chemotherapy? There is actually one study that indicated perhaps increased risk of recurrence and adverse obstetrical outcome if you conceived within the first 6 months of completion of chemotherapy, and that actually matches well with animal studies. In one animal study when they did that, there was an increase in birth defects, miscarriages, and bad obstetrical outcome. Why? Because after chemotherapy you have a lot of damaged eggs sitting around, the ovary has to recover and get rid of these eggs and start making new eggs, and that takes about 6 months. We know that the first 6 months we don't want you to get pregnant, but after that there is no really strong data against it to tell you not to get pregnant, even though most of these studies I showed you looked at beyond 2 years and that becomes the magical number of 2 years that everybody tells you. Again, my sense is sit out the 6 months and if your oncologist thinks it's fine, perhaps there is nothing dangerous beyond 6 months.

And if everything else fails, we have other technologies. Obviously, there is egg donation, and, for those who have frozen embryos, gestational carriers can be used. And there is emerging, an exciting theme, and you will be seeing more on this in the next 6 months, about isolating germ cells that are able to convert themselves into fresh eggs, and this has already been done in animal studies. And I think there is a new horizon in that area that can one day materialize.

Thank you, and now I'm ready for your questions.

**Rochelle Shoretz:** Thank you, Dr. Oktay, for sharing with us some of the latest research on fertility after breast cancer. I'm sure many of those with us tonight have questions for you about your research and future research that may be on the horizon for young women affected by breast cancer. We will now take just a few questions for Dr. Oktay, as he has another speaking engagement this evening. Please use the index cards we have circulated and submit questions. There will be volunteers circulating around, and I will actually begin with the first question --

Are any of the fertility procedures that you described at the end of your presentation covered by insurance? What's the current status on insurance coverage for some of these newer technologies?

**Dr. Kutluk Oktay:** That's a question that cannot be answered with a straight answer, but it really depends on the patient and their insurance coverage and all these different things, and how much they can argue with the insurance company. The general attitude is if this is done before chemotherapy, "It's preventive and we won't cover it." And if it's done after, then they will cover it. But, again, it depends on your insurance plan, which I think is totally nonsense, because they will have to spend more money if they have to deal with it after.

**Rochelle Shoretz:** A few questions have come in, in general, about the notion of preserving eggs. How long can you keep them frozen? What is the viability of a pregnancy using some of the more recent technologies?

**Dr. Kutluk Oktay:** The limit is you. I mean we don't recommend that you get pregnant after the age of 55, but there is really no biological significant aging once an egg is frozen or an embryo is frozen. It's really up to you.

**Rochelle Shoretz:** A question about Tamoxifen and the impact of Tamoxifen on the pregnancy. I know that Tamoxifen is used to stimulate ovulation before chemotherapy, but then we're put on it after treatment how does that impact on the pregnancy cycle generally?

**Dr. Kutluk Oktay:** First of all, Tamoxifen doesn't have a lasting effect on fertility. It's not like chemotherapy. But while you're on it, it's bombarding your ovaries. It keeps stimulating and stimulating, so you may then develop cysts, and then this extra estrogen may cause thickening of your lining. If you're not under close follow-up with your doctors, which usually happens with breast cancer patients, there is a bit of a slight risk of endometrial cancer. At the same time, this is not a drug that you want to use while you're pregnant because it can interfere in the fetal development. But when it's used for fertility, you stop the drug before eggs are ovulated or they are collected, so you don't have the same concern.

**Rochelle Shoretz:** A few questions have come in generally about the notion of a period coming and going during the course of treatment, and I know that a lot of young women call Sharsheret because they're confused as to whether or not that period will return, and, even if it does, what that means in terms of a viable pregnancy in the future. Can you comment on that?

**Dr. Kutluk Oktay:** What happens is that chemotherapy agents have two different effects -- one is regardless of whether they are really the bad ones that cause irreversible damage or the ones that cause a little damage, they also

impact cells that are growing fast. You have two types of eggs in your ovary - one are reserve eggs, they are not growing, and the other ones are ones that are growing with cells that are rapidly multiplying themselves. Most drugs we use will kill those, but those are the ones that make estrogen. But the ones we are concerned [with] are the ones that are sleeping and they're not making hormones, and those you cannot replace. In most chemo treatments, periods may stop but that doesn't necessarily mean that the damage is irreversible. On the other hand, it shouldn't take more than 6 months for the ovaries to recover so that you can start producing eggs from those reserve eggs to produce more estrogen. If your periods stop briefly, that may not necessarily be a bad sign. But if your period hasn't returned for more than 6 months, that may be a significant sign in terms of damage to your ovarian reserve.

**Rochelle Shoretz:** And a final question: What, if any, is the impact of using Lupron, for example, during a cycle of A/C? What impact does that have on fertility?

**Dr. Kutluk Oktay:** In our patient population, we compared women who were on A/C who received Lupron versus [those who] did not, a small group of patients, but we absolutely don't find any difference.

I go around telling this -- there is some information out there that if I put my ovaries to sleep, maybe they're protected against cancer treatment. Unfortunately, these reserve eggs, they don't see hormones. Whether you shut down hormones or you stimulate them, they're not really effective unless there's a mechanism through which they work and we're not aware of. Unfortunately, there is no, right now, good scientific evidence that by doing that you would protect your ovaries. If you do that, I encourage you to do something else, as well, until this issue is clear.

**Rochelle Shoretz:** Final question from Dr. Oratz.

**Dr. Ruth Oratz:** Can you clarify the difference of freezing embryos? I just want to clarify that that's not the same as freezing eggs.

**Dr. Kutluk Oktay:** Sure. When it comes to preservation, depending on whether you have a partner or not, you may have different options. Obviously, if you have a partner or you want us to use a donor sperm, the best thing to do is to freeze embryos because that's the thing we've been doing for the longest time and gives the highest success rates. But if you're single and you want to use a donor sperm, the second option is freezing eggs. That is, after using these drugs to stimulate your ovaries, we collect them. If there is sperm, we fertilize them in the Petri dish and freeze them like that. If there is not a donor, we will freeze them without fertilization. However, those eggs that you don't fertilize are not as sturdy. As a result, pregnancy rates perhaps are about 5 to 10 times lower, but

they are constantly improving. They are constantly improving, and if that option, embryo freezing option, is not available to you, this should be your second choice.

**Rochelle Shoretz:** Thank you. Thank you for your time.

**Rochelle Shoretz:** I had the privilege of working with our next speaker, Linda Roberts, at Sharsheret's second medical symposium, "How Do We Care For Our Children?" presented in partnership with Memorial Sloan-Kettering's Post-Treatment Resource Center. A transcript of that event is also available on Sharsheret's website, [www.sharsheret.org](http://www.sharsheret.org).

Ms. Roberts is a social worker at the Post-Treatment Resource Center, providing individual and family counseling, supportive services to patients with young children, and support groups for patients who have completed cancer treatment. Tonight, she will help us approach a few of the many concerns young women face after breast cancer -- the fear of recurrence, as well as the impact of breast cancer on body image and intimacy.

Please join me in welcoming Ms. Linda Roberts.

## V. Psychosocial Issues for Young Women Post-Treatment: Coping With Fears of Recurrence, Body Image, and Intimacy

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**Linda Roberts:** Thank you so much, Rochelle. It's so nice to be back here. This is a wonderful organization. I cannot believe how each time I get a newsletter, Rochelle just gets seated next to a higher and higher political member of state and you know the last one was next to President Bush. You've really taken this organization to an incredible level.

As Rochelle mentioned, I've been working at Post-Treatment Resource Program for the past 3 years. This is actually my 14th year at Memorial, and for the past 3 years, actually, Post-Treatment -- we call our resource program Post-Treatment - - was started over 15 years ago because so many people came to us after their treatment saying that everyone was telling them that they looked great and should be thankful that they made it and should now move on with their lives. These survivors acknowledged that although they did feel like they were one of the lucky ones and were grateful that they made it, they had still suffered a major trauma and felt out of sync with what they felt they were supposed to feel. To this end, Post-Treatment established all of the services that Rochelle spoke about to further reduce -- especially groups -- to further reduce the isolation that people often feel when they go through a life-threatening illness such as cancer. Much of what I'll be talking about over the next few minutes comes from researched data, but most especially from people who have been through this illness and who have told us over and over the feelings that they are experiencing.

What are some of the common responses to the end of treatment? That there have been major changes -- priorities change, relationships change, and there needs to be some readjustments to these new changes. People often tell us that although the treatment is over, they feel anxious about certain things, not the least of which is saying goodbye to their medical team. We know that although it is not goodbye, the amount and consistency of contact does change as one moves away from treatment. There are no longer monthly, weekly, or even daily appointments, and less contact with your doctors and nurses who have become a strong, supportive, and reassuring team does diminish. Fear of recurrence is something people say they feel, especially around the time of follow-up scans and mammograms -- sorry, Dr. Kolb. Each new pain and ache is no longer just that. Each minor cold and cough may bring on new fears of recurrence. Depression is also a common feeling after one finishes treatment, and I'll speak more about that.

What's going on for the survivor? The feeling of being cheated by a diagnosis so young in life, your friends are well and starting their families. They're on their way with their careers. You may have had time to start a family or you may

already have children -- some, a few, many -- and wanted even more. This is not a time when you expected to deal with a major illness. Searching for “me” becomes a quest for many people. I hear over and over from young people, of the Jewish faith specifically, things like, “I’ve lived my life according to God’s will and I’m a good person. Why me?” Or, “If I’m supposed to be continuing the generations and populating the earth with children in order to follow God’s ways and be able to take care of them, why is this happening to me?” Mourning losses of expectations of dreams for the future.

People say often that they spend a lot of their energy protecting their partners, their families, their friends from the intensity of their own feelings. Often, roles may need to change out of necessity. What you signed up for at the beginning of your marriage may no longer be possible at this time. If your role changes, everyone else’s needs to shift as well, and this may be difficult. If you’ve been the one with certain responsibilities, as is often the case with women, and can no longer do some of these responsibilities, there may be a feeling of failure. There can be a protective kind of feeling such as, “Well, my partners, my friends, my family will get used to life without me anyway,” or even a fearful feeling, “I’ll soon be left for another person.”

People often say how different they feel about their bodies. Some changes are external and visible when looking in a mirror or such as when someone else is looking at you, and some changes are internal in terms of how you perceive your body after such treatment. One of the losses that we hear about is the loss of sexual feeling, the loss of libido, the loss of desire, or the wish to connect with a partner. So what could cause loss of libido? Few people are interested in sex when their life is threatened. For many, they’ve been forced to make a choice between sexuality and fertility and survival. Premature menopause, which has been mentioned, is common after treatment. Symptoms are often more severe than the slow changes that happen during a natural menopause later on in life. One such symptom is vaginal dryness, which may cause pain during intercourse. It’s not unusual to worry that one’s partner or future partner will be turned off by the changes in their bodies or even by the very word “cancer.”

Let me say a few words about the single woman who may not have a partner. Depending on the community one lives in, a diagnosis of cancer may carry a stigma and can really interfere with the way one is viewed and one’s marriageability. We hear often how people feel they are “damaged goods.” The worry about being able to have children is very real. However, Dr. Oktay’s research is a little bit heartening. Once a person is diagnosed with cancer, one may think that they’re flawed, both physically, where the quest for the perfect body may no longer be possible both in your own perception of yourself and in your potential mate’s quest for you, and emotionally. You may hear from others that you need to lower your expectations, to be more realistic given what you’ve been through. I prefer, and we prefer, to say that you should modify your

standards, not lower them. Open your eyes a little bit more. Maybe somebody that you thought wasn't a bargain is. You may find a better husband in someone that you may not have looked at before. Cancer or no cancer, let's face it, you have a better chance to find someone if you open your eyes a little bit. That being said, when does one bring up cancer with a prospective partner? And the answer is that there's no real right time. There's no real answer, but we do know that there are two wrong times -- not on the first date and not before you're about to get intimate.

Let's talk about myths everyone faces, married or single. Number 1 is that sexual activity causes cancer. It does not, but it is common to believe, especially when cancer starts in an area of the body that is seen as sexual, such as the breast. As well, resuming sex after treatment does not increase chances of cancer returning. How many of you have heard or think you have heard from other people that cancer is contagious? Anybody here? This is a very sophisticated crowd, because we usually hear people telling us that. Well, cancer cannot be passed from person to person in any way, in close contact, in any way. Another myth is that sex is harmful to the patient, to the survivor, to their partner, and some people stop having sex because they fear that it will make the cancer worse. It's common to worry about hurting your partner or embarrassing your partner. Sometimes people say, "I can tell that my husband or my boyfriend is turned off," but what we hear often is that when we actually sit down with the couple is that the husband is really anxious about these changes that I spoke about earlier and worried about hurting or further harming the scar, the implant, the incision, and that's really what's going on.

What are some of the keys to staying sexually healthy after cancer treatment? Well, it's important to gather facts, accurate information such as what's taking place tonight to help attain more realistic views and expectations. This will also ultimately help to dispel myths that either you believe or that you're hearing from people over and over. To resume sexual activity slowly, to take it slow -- intercourse does not have to be the end result. There are different ways to connect, through tenderness, through touching. A lot of people are afraid to be tender. They're afraid that their partner is pushing intercourse, the end result, but this is where you don't have to be afraid to be intimate without having to have the intercourse. It's also important to remember what your sexual life was pre-cancer. What were your attitudes about intimacy? What was the frequency of your sexual activity then? What were your feelings about yourself and your body image pre-cancer? It's important to remember that those usually don't go away and that's what might be going on now, as well.

It's important to have good communication. This is a time where it's easy to withdraw and not want your partner to be burdened by sharing your fears or sadness. And the problem with that is that not only leaves you but your partner more alone to cope with this pain. It's also easy to accuse each other at this

time, “You never touch me anymore,” or “Why are you withdrawing from me?” instead of, “I miss our sex life. Let’s talk about this.” This is true cancer or no cancer, and this is where cancer survivors may actually have the edge if there is any silver lining to be gotten from this, because the need to communicate openly and frankly with a partner is always important. This may also be an opportunity to develop skills that are very strong that any couple could develop to maintain a strong relationship.

If anxiety or depression, which is very common during this time, is what you’re experiencing, treating it through support, counseling, and medication can be helpful as well. The lack of desire, as we mentioned, is often a result of these feelings and a very real issue. It’s also important to laugh a little bit. This doesn’t have to be so serious. You can be playful, and even mistakes made in the bedroom can be laughed at.

The reason you’ve seen so many sexual health clinics open in oncology settings is that we have so many survivors who want a good quality of life, and we have come to realize that quality of life, as Rochelle has said, is very important to survivors. In these clinics, which usually consist of a few sessions either alone or with your partner, information and support are gotten, practical strategies. It’s a place to address fear, address issues of body changes, and it’s to enhance communication with your partner, to learn to enhance.

Whether you go for sexual counseling or not, these are some of the things that you can do to make things better -- expecting the changes that have occurred as a result of cancer treatment and work with these changes, decrease physical tension, pursuing activities that have been relaxing for both you and your partner before cancer became a reality, knowing that it’s okay to cry together about these losses and resultant changes, and to go out. Go to a restaurant, to a movie, for a walk. Sit on a bench outside. Try to recapture what you liked best about your spouse and about each other before cancer struck.

These are some of the resources at Memorial Sloan-Kettering -- the Post-Treatment Resource Program, where I work and which has many different programs, educational seminars, counseling individual/couple, and support groups. There is a special health program at Memorial. This is the number (212) 639-8570. And I know there’s a sexual health program here at Cornell and at most oncology centers. Like I mentioned, this is a new thing that people are really starting to realize how important it is.

And there’s a booklet, for those of you who have not seen it, *Sexuality and Cancer*. It is produced by the American Cancer Society. It is a fantastic booklet, which I highly recommend. It’s got illustrations. It’s very detailed. It’s written by a well-known sex therapist, Leslie Schover, and you could get it by calling the American Cancer Society, whose number I believe is 800-ACS-2345. Thank you, Rochelle. Thank you very much.

**Rochelle Shoretz:** Thank you, Linda, for beginning this very important conversation. It is certainly comforting to know that so many of us face similar concerns -- perhaps concerns that seemed too personal to share. You've given us a wonderful framework to begin exploring these issues with our loved ones and with each other.

It's fitting to introduce our next speakers, Jill Dennis and Lisa Goldberg, after Ms. Robert's presentation. As women diagnosed with breast cancer at a young age, many of us begin to reflect seriously on our eating and exercise habits after treatment. Perhaps it is an element of control -- something that we can manage after the chaos of treatment. Tonight, Ms. Dennis, an occupational therapist right here at Cornell, and Ms. Goldberg, a certified nutrition specialist at Memorial Sloan-Kettering's Outpatient Breast Center, will tag team the subjects of eating right and staying fit after cancer treatment. Please join me in welcoming Jill Dennis and Lisa Goldberg.

## VI. Importance of Healthy Nutrition and Exercise After Cancer Treatment

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**Jill Dennis:** Thank you, Rochelle and Sharsheret, for having me this evening. I'm very honored to be here. This is my first time coming here, and I'm happy to share this information that I'm about to share with you.

As she said, my name is Jill Dennis. I am an occupational therapist here at Cornell. And you're probably wondering what occupational therapy is and how it pertains to you. And I'm here to tell you that occupational therapy is a therapy that helps people become re-engaged in their occupations of daily living, or as we like to say "activities" of daily living, and this can be anything as basic as dressing to go grocery store shopping again, becoming active, maybe even dancing, doing some salsa in a nightclub, you never know. We want to get you back into all those activities. But in order to do all of those things, you need to have the endurance, you need to have the strength, and you need to have control over your lymphedema system if that is a concern to you on your course with breast cancer.

Moving on, things to consider -- these are the topics that I'm going to discuss -- Why exercise? For the prevention or maintenance of lymphedema, strengthening for osteoporosis, stay healthy and fit, to be able to lift more than 5 pounds, and to engage in your activities of daily living.

Really quickly, I'd just like to find out how many of you have heard after surgery or treatment that you cannot lift more than 5 pounds? Okay. We'll get to that a little bit later.

To talk about breast cancer, you have to talk about lymphedema. Most women who have had a lymph node dissection, 40 percent of those women they say are at risk for developing lymphedema. We want to make sure that we can manage that lymphedema or prevent that lymphedema as much as we can. What is lymphedema? Just really quickly before we move on -- the main role of the lymphatic system is to return protein molecules to the bloodstream. Lymphedema occurs when the transport capacity of the lymphatic system falls below the level of the normal lymphatic protein load creating an abnormal accumulation of protein-rich lymph in the tissue. What this means is that if your lymph nodes have been removed, the remaining lymph nodes still have to manage the same amount of protein that is running through your body. Some of those lymph nodes can handle that load and some cannot, and if it cannot handle that load, you end up with lymphedema. Just because you had lymph node removal doesn't mean that you will develop lymphedema. It is just a possibility that you may.

There are two types of lymphedema -- primary is when it is present at birth or developed at puberty or adulthood. The other is secondary acquired lymphedema, which is as the result of surgery, radiation, infection or trauma, specific surgery with lymph node removal. And if the lymph nodes are removed, there is always a risk of developing lymphedema. It can develop immediately post-operatively or weeks, months, even years later.

And to give you an example, I was reading a research article of a woman who lived 20 years post-surgery. She decided one day to go out and do gardening. She loves to garden. It was hot, really hot in the sun, and she started doing all of her exercise, and it was repetitive motion over and over again. By the end of the evening, her arm had blown up to the size of a balloon and she had developed lymphedema 20 years post-surgery.

It can also develop when chemotherapy is unwisely administered to the already affected area. Infection is a high risk as well. If you get a little nick under your nails, they always say, "Don't cut your hangnails." Have you heard that after surgery? So there's no room for infection. When you get an infection in your arm, for example, that means increased blood flow, which means increased protein, which means more lymph to the arm, and an increased load that your lymph nodes have to handle.

What can we do for all of these symptoms? At least when it comes to exercise, what can we do about it? We do resistive and aerobic exercise, which are both effective tools in prevention and management of lymphedema, strengthening for osteoporosis, strengthening muscle groups affected during surgery, especially your abdominals and your pectorals, and maintaining your upper extremity range of motion. If you have had surgery, you may have noticed that after surgery you are a little tight in the underarm area. So to maintain that range on your strength it is vital to maintain that range of motion.

Resistive exercise -- this is a controversial topic for some, not for others. I am a very big fan of resistive exercise, and I'll tell you why. But first what is resistive exercise? Do you use Thera-Band, which is that elastic material? Some of you may be familiar with it. Or, do you use weights and how much weights should you use? With my patients, I'll generally start them with about 2 pounds and work their way up as they can tolerate. Of course, you have to do this with a consult with your doctor and a licensed therapist. The muscle contractions during the resisted weight squeeze the lymph vessels, which are stimulated to contract and move the fluid within it upward approximately. It's important to realize you should engage in resistive exercise if you have lymphedema or if you don't have lymphedema to maintain your strength and your endurance.

A recommended technique that I do with all my breast cancer patients is to begin your arm exercises from top to bottom, and the way you can think of it is:

shoulder-elbow-wrist and return back to your shoulder. And the reason we do it this way is we copy the same techniques that they do in manual lymphatic drainage if you do have lymphedema. If you have lymphedema in your right arm, you want to open the passageway above your left shoulder, so that you're creating a pathway for the lymph to move. You do the same thing when you're doing exercise. You're going to start with some basic shoulder elevation and depression, then you're going to move the shoulder forward and back, then move to the next joint -- bicep curls. Then you're going to do wrist flexion and extension, and conclude by finishing with the shoulders again so you've opened up that pathway for the lymph to flow. It's important to realize you can do this both with weights and without weights, depending on what your doctor or your licensed therapist has to say, and you work together as a team to determine what is most appropriate for you.

Another reason for resistive exercise, with hormonal therapy or chemotherapy especially, is peripheral neuropathy, where you start to get a little numbness in your fingertips or maybe your toes, and this may interfere with your ability to do buttons or the finer things that you can do in your daily activities. You can get occupational therapy for strengthening and maintenance of those muscles in your hand. When you can't really feel your fingers, your fingertips, you tend not to use them as much, which means decreased strength. We want to keep them strong by keeping you engaged in your exercises.

Aerobic exercise -- Whenever you exercise, you should do breathing all the time. The effects of aerobic exercise originate from the thoracic duct, which means that you're increasing your intra-abdominal pressure, allowing the lymph to flow throughout your entire body. So: cardio, cardio, cardio. You need to do your cardio to keep breathing, to keep moving fluid through your body. The best one I will suggest is swimming. It is the best exercise that you could do. It's great cardio. You're underwater. There's pressure with that water to help facilitate moving the lymph, and also it's good resistance under that water you're constantly pushing. It's the greatest exercise. So get to swimming and swim as much as you want. If you are going to go to the gym, stick to the cardio gliding machine or the bike. I would avoid the step machine, and the reason I avoid the step machine is because it's very jerky and whenever you have a jerk at the end of an exercise, it causes a rush in blood flow with a rush of protein, which means more lymph. So just avoid those jerky exercises. Keep yourself gliding in constant motion.

How much exercise is too much exercise? I would recommend if you are doing weight training or without weight training, 10 to 15 repetitions are recommended to start, and then adjust according to your doctor and your therapist. Perform these exercises daily and monitor responses to ensure safety and effectiveness. Repetition is tricky. You don't want to do too much, but how much is too much? Your body needs the oxygen with that repetition, but, like I said, if you have those

jerky movements, you don't want to force too much lymph into that system. Just remember to stay in motion. That's the best advice I can give you -- walking, cycling, cardio gliding, and swimming.

Adjunct to exercise would be manual lymphatic drainage, which is where they route your lymph to help reduce your lymphedema. You should do this with exercise. It is most beneficial.

At Memorial Sloan-Kettering's Department of Integrative Medicine -- I actually worked there for a little bit and ran the exercise group there for a couple of months -- they incorporate medication, acupuncture, massage, nutrition, and reflexology all geared toward cancer patients.

Research regarding exercise -- many articles available support aerobic exercise. However, not many discuss the advantages or disadvantages of resistive exercise, and this is why this is such a controversial topic. Everybody is going to have a different opinion when you're out in the field as to whether to do weights or not to do weights. The only thing I can say is that from my experience, I use weights with all of my breast cancer patients and never once has it increased edema. It has always managed or reduced lymphedema. I know at Sloan-Kettering right now they're starting up a research to publish a paper which discusses weight training with breast cancer patients post-treatment, because we've seen these amazing results. It's just that nobody knows about it yet as much. They want to get it out there and say, "Do your resistive exercise because it's so good, but please do it with the consult of your doctor and your therapist."

Where to exercise? At Memorial Sloan-Kettering, at Integrative Medicine. The instructor is Donna Wilson. She's a nurse. She's a wonderful person. You can just go to [mskcc.org](http://mskcc.org). and in their search engine you type in "Integrative Medicine," and it comes up with all their programs, including meditation, exercise, and all of that. I taught these following classes, which are still there and Donna teaches them -- chair aerobics, which focuses on your lungs, your chest, your arms, and your legs; step aerobics for strengthening, for osteoporosis; and a fitness movement group specific for women breast cancer patients. It encompasses elements of the Focus on Healing program, which is a dance program for women with breast cancer. All of these incorporate resistive exercise.

A final note -- You are strong. You are beautiful. You are feminine. You are gorgeous. You are more than a survivor. You are a thriver!

**Lisa Goldberg:** Hi everyone. I'm going to be talking to you about breast cancer and diet and how does diet actually fit in.

From the moment many of you were diagnosed, someone, whether it was your physician, a family member, or a friend has been telling you what you can and cannot do about your breast cancer. You're told which tests or procedures you need to have. You're told what type of surgery you're going to get. You're told which medication you need to take and radiation therapy recommendations. You're planning appointments based on other people's schedules, which is inevitably overwhelming and can result in leaving a lot of people controlling your life.

One area where you can have some control and possibly influence your diagnosis is through your diet as well as your weight. So what we're going to be talking about today is a little bit about obesity, and of course weight gain. I actually had somebody ask me a question when I first got here about the effects of weight gain now that they've gone through treatment. We're going to look at some of the new dietary guidelines for 2005. We're going to talk about phytoestrogens, these are plant estrogens, and how they might impact breast cancer. We're going to touch on complementary and alternative therapy, a little bit about the supplements, importance of calcium in bone health, and then looking at alcohol and some of our take-home points.

Is there a link between diet and breast cancer? Yes there is. Dietary factors are involved in the development of breast cancer. This is really important to establish because these are potentially modifiable while most known risk factors for recurrence of breast cancer are not modifiable. If we look at all the different risks associated with breast cancer, such as gender, age of menarche, pregnancy, hormone replacement therapy, these are non-modifiable. But if you look at obesity, diet, physical inactivity, and alcohol, they are modifiable. And what's interesting about that is there is one common theme between all these risk factors, and that's estrogen, and we're going to see how obesity, diet, physical inactivity, and alcohol can actually influence estrogen.

Currently, trends in the U.S. -- I'm just going to touch a little bit on that. Less than half of U.S. adults are at a very healthy weight right now, which is kind of scary because we do have an obesity epidemic. Nearly 2/3 of U.S. adults are overweight, which means about 65% are overweight, and nearly 1/3 of U.S. adults are obese, which is about 31%.

For some being overweight is subjective. However, in the clinical practice we have specific criteria to define normal, overweight, and obese, and one school that we use is the Body Mass Index. The Body Mass Index is a way of looking at your weight relative to your height. So if you take the left-hand column and you find your height, then you look for your weight within the grid, that row on top will then be your Body Mass Index. For instance, somebody who is 5'4" and weighs 128 pounds would have a BMI of 22. To interpret this particular number,

anybody between 18.5 and 24.9 is considered normal weight, anybody between 25 and 29 is considered overweight, and above 30 would be considered obese.

And how does obesity come into play with breast cancer?

What we do know is estrogen gets stored in our adipose tissue. Adipose tissue is where your fat is stored. Knowing that estrogen can stimulate breast cancer, being thin can lower the amount of adipose tissue and in turn lower your overall estrogen levels. Clearly, this is where diet can make a difference.

We also know that weight gain does occur frequently in patients post-diagnosis. In fact, an average of 5 to 15 pounds has been seen in over 50 % of patients who have gone through adjuvant chemotherapy, if not more. One of the reasons for weight gain, that seems to occur, is when those who are premenopausal and are now postmenopausal, this can certainly influence weight gain. The other indicators are maybe the adjuvant chemotherapy themselves, the onset of a premature menopause. Some of the combination therapies, the treatment counts are better now with combination therapies and this potentially can lead to an increase in weight as well.

We also are using premedication that helps with nausea and vomiting, such as we're using steroids or we're using antiemetics. All of these agents also might contribute to some of that weight gain. Other possible causes are basic increase in energy intake. You're more sedentary as well, so there is less physical activity, possible depression, and maybe an influence on your rate of metabolism.

Also, what I've seen a lot is changes in body composition. I always get that, "Oh, I'm feeling kind of wide around my waist." What does this change in body composition mean? Basically, the distribution of body fat may also affect breast cancer. Abdominal weight gain seems to carry more risk of disease than weight over the hips, the buttocks, and the lower extremities, and this central body fat distribution is associated with multiple hormonal and metabolic changes, including insulin, as well as higher estrogen in fat tissue.

Knowing all of this and how your weight can affect breast cancer, how do you design a healthy diet? The American Institute for Cancer Research has created the new American plate. The center of this new American plate is a variety of fruits, vegetables, and whole grains, as well as beans. They are naturally allowing calories and should cover at least 2/3 of your plate, 1/3 of your plate or less should come from animal sources. Really, what's important about all of this is when you're designing a healthy diet, you actually need to know how many calories you should be consuming. Back to your BMI -- knowing what that BMI is. If you need to reduce weight, it's about 7 to 9 calories per pound. If you're looking to maintain the weight, it's about 12 to 14 calories per pound. And if you're looking to gain weight, it's 15 to 16 calories per pound.

Going [along] with the new dietary recommendations that the American Institute for Cancer Research is promoting, the USDA is now promoting their new dietary guidelines. And what they're looking at is an increase in your fruits and vegetables, close to 9 servings per day, as well as whole grains, and there is a big emphasis on whole grains. Also, and most of these foods are plant-based and a limited amount of protein, not an excessive amount. If you look at the health benefits of the fruits and vegetables, they have components called phytochemicals. These are plant chemicals that exist in your fruits and vegetables, and it's a wide variety of fruits and vegetables that should be consumed. Phytochemicals are substances that naturally occur in food. They are compounds that protect plants against insects. They also exert an antioxidant-like activity, or a hormone-like activity, and really the best way is to get it from the food sources. These are just some examples -- the broccoli and the spinach have indole. We hear a lot about watermelon and tomato having lipoprotein, and the best way is really get it from your food. It has a synergistic effect. One of the take-home points is that supplement usage really has not shown to be beneficial.

In giving that, another phytochemical that we hear a lot about are the phytoestrogens. Are phytoestrogens helpful or harmful for the breast cancer patient? Did you know that the risk of breast cancer varies substantially throughout the world, and population studies indicate that the Asian diet actually has higher soy consumption with substantially lower breast cancer mortality than in Western countries where soy consumption is minimal? Consumption of soy food is 20 to 50 times more than American women, while breast cancer mortality is 2 to 8-fold less. Although the overall Asian diet is quite different than the American diet, soy has been constructed as a possible explanation for the dietary impact on breast cancer mortality. However, what do we actually know about soy and how does it impact the breast cancer patient?

Just quickly, phytoestrogens are composed of different phytochemicals. You have three major ones -- you have the isoflavones, the lignans, and the coumestans. The major food source for an isoflavone is soy. You hear a lot about flaxseed now, but lignans would be the flaxseed, and coumestans would be alfalfa. If you look at the chemical structure of soy, it's very similar to that of estrogen, and when you sort of overlay them, they can be superimposed. Really, what we don't know is if this helpful or harmful in the breast cancer patient, and there has been a lot of mixed data on this. We know on some studies that this has been shown to have some beneficial effects, but in other studies it has been shown to have a negative impact. We also know that most of the studies looking at soy are looking at the whole soy food. So they're looking at the soy, not the soy bean, soy protein, not the American version of the soy diet, which really incorporates in your soy protein shakes, your SnackWell cookies.

With this surge in our low-carbohydrate environment, where we're looking at decreasing our carbohydrates, and you hear a lot about that, supermarket shelves are now being saturated with alternatives. And so you might see "carb control" on your bread products. What they're adding in there is soy fiber, soy flour, soy protein. They're actually increasing the fiber content and decreasing the carbohydrate content. But what is this doing to somebody who has a history of breast cancer? Who knows? And this is over the last three to four months that I've noticed a big surge in these types of products. With that in mind, not knowing what soy does on the breast cancer patient, at Memorial we are currently doing a study to find an answer to this, and the purpose of the study is really to determine the effects of soy protein on normal and cancerous soft tissue.

What are the take-home points here? Since it is not known whether large doses of soy are protective or harmful for women with a history of breast cancer, several health organizations such as the American Cancer Society, American Institute for Cancer Research, Memorial Sloan-Kettering, are suggesting that you eat a moderate amount, and that's about 2 to 4 servings.

Just again, to touch on complementary and alternative medicine -- you look at the evolution of medicine. In 2000 BC you had, "Eat this root," and then as we evolved, "Oh, that root is infected. Say this prayer." "No, that prayer's superstition. Drink this potion." "That potion is snake oil. Swallow this pill." "That pill is ineffective. Take this antibiotic." And here we are today, "That antibiotic is artificial. Eat this root." But what do you really know about that root? Are you really taking the root? Once it goes to a manufacturer, it's actually processed, so it's no longer natural. And, really, what do you know? The bottom line is the FDA does not regulate the supplement industry. Some supplements actually have misleading claims on their labels and may even be harmful in certain circumstances. Manufacturers are not required to establish standards for controlling the safety, content, quality, or dose recommendations, and they're also not required to print side effects. There is also nutrient drug interaction, so if you're on other medications, this might potentially interfere.

There are websites that you can use that are available, such as Memorial Sloan-Kettering has a website about herbs, and this is a database that looks at different herbs, botanical, and other products. The National Center for Complementary and Alternative Medicine, by the NIH, American Cancer Society, and those are free of charge. And then you have Natural Database and Consumer Lab.com that are for a fee, but they also provide very useful information.

Just quickly, I know Jill talked a little bit about osteoporosis, and I'm glad she did talk about that because that's a big problem. We don't really think about that when we're in our 20's or even our 30's. However, that's the time when we actually should be looking at osteoporosis. When we are in our 20's, we do

reach our peak bone mass, and each decade of life after our 20's our bones start to weaken. What we know is adequate calcium intake will slow the rate of bone loss and reduce the risk of fractures in most bones in older adults. However, what is alarming is the average American consumes only 600 mg of calcium a day, yet the National Academy of Science recommends 1,000 mg of calcium for adults 19 to 50, and 1,200 mg of calcium for adults over the age of 51. Of note, some of these medications that you might be taking, the Aromatase inhibitors, actually are reaching your bones, so it's even more important to be getting your calcium in at that point, and make sure it's a calcium that has some vitamin D in it.

Finally, just on alcohol -- it's a major source of calories for most patients, and there are several studies that have actually linked alcohol to breast cancer in several different ways -- it might make more estrogen receptors and, therefore, increase the sensitivity of tumor cells to the same level of estrogen, or it may increase estrogen levels overall. Again, increased estrogen increases one's risk for breast cancer. The type of alcohol is irrelevant, so it doesn't matter if it's wine or beer, and increased drinking can lead to increased risks. Basically, just reducing your amount or avoiding it is probably best.

And just to sum it up quickly, if we look at current recommendations for breast cancer in diet, they're primarily aimed at maintaining a healthy body weight and dietary lifestyle strategies that reduce estrogen stimulation appear to be helpful. There really is no direct link between diet and breast cancer, and there is no specific diet, but, clearly, following a calorie-controlled diet, consuming high fiber foods, limiting your alcohol, getting some exercise in, making sure you're getting calcium is certainly a wise decision. Thanks.

## VII. Impact of Breast Cancer on Jewish Ritual and Spirituality

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**Rochelle Shoretz:** Thank you, Jill. Thank you, Lisa. Those were extremely practical guidelines for all of us. Thank you again for joining us.

I'm going to sort of breeze through my own presentation, and I thank you all for coming back. While I'm speaking though, feel free to use your index cards to write down questions you may have for our panelists. And I promise to be brief.

As the only national organization addressing the needs of Jewish women facing breast cancer, Sharsheret has become a valuable resource for those interested in the impact of breast cancer on the lives of Jewish women, health care professionals, Jewish leaders, communal organizers. My brief remarks tonight will touch upon some of the ways in which breast cancer survivorship affects Jewish culture, observance, and spirituality. My hope is that this presentation will provide a culturally-sensitive perspective on life as a breast cancer survivor for those who are unfamiliar with that perspective. For those already living beyond breast cancer, I hope my remarks provide the sort of comfort that comes from hearing your own story and knowing that you are not alone.

Not long ago, a reporter from the Wall Street Journal called to discuss survivorship and asked me a question that caught me off guard. She wanted to know if the term "survivor" was more troubling to Jewish women who may associate the description "survivor" with someone who has lived through the Holocaust. Perhaps it is a function of our age, but most of the younger women of Sharsheret have not expressed that concern to us. Concern about the term "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 that tempting fate – some call it the evil eye or Ayin Ha Rah, will in some way create destiny. Some refer to it as "Al Tiftach Peh El HaSatan" -- "Don't open your mouth to Satan." 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 an age of Races and Walks, celebrations of survivorship by every major cancer organization. While many women take up the cause and embrace the term "survivor," some Jewish women are fearful of that very term.

For other Jewish women, many in the ultra-Orthodox or Chasidic community, breast cancer is still "taboo" -- a subject one doesn't discuss, perhaps even with family members. There are those for whom breast cancer is considered an affliction, likely to interfere with potential marriages and family status. The rationalization is as follows -- "If someone recognizes I have had breast cancer, it will make it more difficult for my daughters and granddaughters to find husbands." And in some communities, that fear is grounded. A cancer diagnosis

will affect potential partnerships. The fanfare with which many breast cancer patients approach survivorship, therefore, is replaced with the same silence that accompanies diagnosis and treatment.

For other young women who have contacted Sharsheret, transitioning beyond breast cancer can bring with it the opposite -- the search for community -- others who understand the journey that has just ended and the new journey about to begin. During active treatment, younger women can be too busy to reach out for support -- juggling medical appointments, treatment schedules, careers, families, and social responsibilities. But once the chaos of active treatment ends, many young Jewish women seek a community within the community, a place to turn to for guidance and reassurance.

When Sharsheret was founded, many predicted that our community would be a narrow one, that only Orthodox or observant women would reach out to an organization that targeted Jewish women facing breast cancer. But a significant number of the women who call Sharsheret identify themselves as unaffiliated Jews. Sharsheret has become a community of sorts for women who may not be satisfied with other elements of organized Jewish life, a safe place to explore tradition and spirituality within the context of a shared experience.

For those who are already entrenched in a Jewish community, the transition to life beyond breast cancer can trigger the search for other community members who understand and appreciate the ways in which breast cancer affects Jewish women. Since Sharsheret's founding, perhaps the most frequently asked question I field about the organization is -- Is there really a need for a breast cancer organization dedicated to addressing the needs of Jewish women? With three years behind us, I can answer with confidence. Yes, we certainly do.

Of course, women of all religions and cultures share common concerns and strategies in life beyond cancer. Prayer and meditation, for example, are two ways in which women across the spectrum draw renewed strength in spirituality. A few of the women of Sharsheret, for example, found comfort in prayers they recited during active treatment, which they have now incorporated more completely into their lives post-treatment. Some have been enriched by Tehillim, Psalms, often recited on behalf of those facing illness. Others created their own prayers as a meaningful rite of passage to life beyond cancer.

But beyond prayer, I'd like to touch on some of the unique ways in which breast cancer affects the Jewish woman, particularly in life after active treatment.

First, using the Mikvah or ritual bath can be a time of renewed healing. For some, immersion in the Mikvah is a custom associated with marriage that can take on added meaning after surgery and treatment. Using the Mikvah can also be a time to embrace new traditions, as the waters and all they symbolize bring

hope for health. For others, immersion in the Mikvah can force a confrontation with body image and sexuality in the ways Linda Roberts outlined for us in her presentation. It can be a trying time, particularly if discussions about intimacy and body have been ignored during the hectic pace of active treatment.

Wearing a wig or a hat beyond active treatment can raise a second series of concerns for the Jewish cancer survivor. Many assume that wearing a wig or a hat must be easier for those observant Jewish women who cover their hair after marriage. But covering your head because you've embraced a positive religious ritual is very different from covering your head because you've lost your hair to cancer. And for single women who cover their heads during cancer treatment, doing that which is traditionally associated with marriage only complicates already complicated emotions. Many young Jewish women living beyond breast cancer struggle with hair-covering. For some, wearing a wig post-treatment can be a painful reminder of cancer, a continuation of the struggle to cope with the side effects of a traumatic diagnosis. Others find added meaning in the ritual, and choose to cover their hair with a deeper appreciation for its inherent beauty.

Perhaps one of the most urgent subjects for the young women of Sharsheret is the subject Dr. Oktay addressed earlier, the subject of fertility and the related subject of parenting, both of which have tremendous emphasis in our communities, particularly in those communities in which 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. For those with cancers that were hormone receptor-positive, fears of recurrence are triggered at the mere thought of the hormones coursing during pregnancy.

These are fears that are played out over and over again for young Jewish survivors -- fears that add another dimension to Jewish milestones, like weddings and Bar Mitzvahs, where many cancer survivors are likely to be thinking, "I hope I live to see this moment, too." These are fears that weigh heavy during Jewish holidays, particularly during the New Year holidays of Rosh Hashanah and Yom Kippur, which trigger serious introspection about matters of life and death. At the same time, these Jewish milestones, these Jewish holidays, can be a time for celebration -- for affirming life and embracing the challenges of survivorship. Through organizations like Sharsheret, young Jewish women can embrace those challenges together in an atmosphere of confidentiality and respect.

We are fortunate to live at a time when the discourse about survivorship is ripe. National cancer organizations like the Lance Armstrong Foundation and the National Cancer Institute are initiating research and developing resources, some of which you received in your information packets this evening. As the only national organization addressing the needs of Jewish women facing breast cancer, Sharsheret will continue to identify many of the unique concerns of

Jewish breast cancer survivors as we embrace the challenge of survivorship together.

## VIII. Question and Answer Session

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**Rochelle Shoretz:** I would like to welcome back all of our speakers for the Question-and-Answer Session, and thank you all for your patience this evening.

This is really an opportunity for all of us to submit our questions to the distinguished speakers and get that one-on-one attention that we often covet in the course of our appointments. If you haven't already done so, please circulate your index cards. The volunteers will be running around the audience. Given the hour, we likely will not have time to address every personal question, so if you could please keep your questions general in nature, it will be easier for us to get to them.

I'm going to start, actually with the first question for Dr. Oratz. When does a breast cancer patient become a breast cancer survivor? I know there is a 5-year mark, but time and time again I get calls from women who say, "I don't know what I am. Am I a patient? Am I survivor? I don't feel like a survivor, but I'm certainly not a patient." When exactly is the transition to survivorship?

**Dr. Ruth Oratz:** I'm actually one of those people who has a little bit of trouble with that word "survivor," because I think that we don't have a clock ticking away in our bodies that says, "On this day at this time something magical is going to happen." I think that we are all surviving every day, no matter what it is that's going on, whether we have cancer that's under active treatment, whether we've completed a period of treatments and for that moment in time, hopefully for many years, we're well without cancer, but for all of us our lives are continuously a process, a project, and a challenge. I don't really use that language, Rochelle, and I think that we have to look at each one of our lives as an arch that we go through in this process and face the challenges that we have to look at each day, each week, and each month. I don't have that clicking alarm clock that changes your status.

**Rochelle Shoretz:** Thank you. Dr. Kolb, two questions for you. One question about timing of imaging, and the question is -- What time in the menstrual cycle should a woman make an appointment to be imaged?

And a follow-up question to that -- Post-mastectomy, if you could comment on some of the screening differences for women who have already had breast tissue removed, what differences there might be in screening.

**Dr. Thomas Kolb:** As far as timing, for mammography and for ultrasound there's no difference. It makes no difference when you are in your cycle diagnostically. However, your breasts are more tender towards the latter part of your cycle, and so mammography becomes much more uncomfortable. If you

get to the point of discomfort where the mammogram can't accurately be performed, that's a problem, but that's very rare. There is no point in subjecting yourself to that discomfort if you come earlier in your cycle.

In terms of MRI, that's very important that it be done in the early, early part of the cycle -- within a few days after the period, within the first week. After your second part of the cycle, breasts are much more active physiologically. An MRI can have a lot more false positives in addition to the high false positive rate, so you definitely want to have MRI's done the early part of your cycle. Physical examination, breasts become more lumpy later in the cycle as well, and it's much easier. For whatever physical examination provides, it's better for it to be done early on in the cycle.

The second question was post-mastectomy. Post-mastectomy there are a lot of issues. One is there is a lumpectomy site. Post-mastectomy for the other side or for the mastectomy site? For the mastectomy site, there is no imaging after mastectomy. We only image the remaining breast. Whether there is reconstruction or not, there is no imaging required for that site -- for the mastectomy site. With TRAM flap reconstruction, which has autologous grafting to that site, there are some that do image and do mammography. There is, again, a high false positive rate because of a lot of fat necrosis, because it's really fat that's being brought up to the breast tissue. In general, most people will not image the mastectomy site with any imaging.

**Rochelle Shoretz:** Thank you. A question for you both, actually -- One of the questions that comes often to Sharsheret and I see in certain respects in some of the questions that have come up here is who is the conductor of the orchestra post-active treatment? Is the oncologist the person who is supposed to be helping you set up your schedule? Is the radiologist the person who is supposed to be helping you set up your schedule? How do you get the two to work together? I find that a lot of women who call the organization are confused about who it is that's supposed to be controlling the frequency with which one is followed up after active treatment.

**Dr. Thomas Kolb:** In most cases, the conductor is the clinician, and then it's the breast surgeon or the oncologist. It doesn't happen to be that way in my case, but that's a separate issue. I don't pay somebody to provide bare minimum standard of care. I do a lot of the conducting and do physical examinations. I think radiologists, anyone who does an ultrasound, should be prepared to do an accurate physical examination, and act on that physical examination in the face of a normal ultrasound as well. If you're going to do an ultrasound for a palpable lump, you better know how to physically exam the breast. That's not standard of care for radiologists. In general, the clinician, the breast surgeon and the oncologist, in the real world outside of my world, are the ones who conduct treatment and follow-up visits for screening as well.

**Dr. Ruth Oratz:** I agree with Dr. Kolb. I think that each individual patient is going to have a team, and it seems like this team is huge. There's the medical oncologist, there's the radiologist, there's the surgeon, there's the radiation oncologist, and then there are all of the other health care professionals who are very important members of that team -- for nutrition, for psycho/social support, for exercise. There are the nurses who cared for you during your treatment and with whom you may have developed a close bond and who may be tremendous sources of both support and information. There are even the people who draw your blood in the lab who know how to get that little needle into the vein. It's an army of people who are part of the team that has been taking care of you, and you need to see all of them. You really do. When the person who does your breast imaging says, "I'd like you to come back in 6 months for the ultrasound," don't turn around and ask the doctors, "Gee, should I do that?" It's like the kids playing the mom against the dad.

Really, I think, especially here in New York, we are very lucky to have so many wonderful physicians who are experts in their field, who are really committed to keeping you healthy. I would take their advice and I would listen to them. If you feel that there really is a conflict and that you're just always at the doctors, then yes. We can kind of try to streamline and tailor and coordinate those visits so that you don't feel that you're the perpetual patient, but it is important that not only your care be multi-disciplinary, but that your follow-up be multi-disciplinary.

**Rochelle Shoretz:** Thank you. Linda, for you -- How does a young survivor know when it might be time to see a health care professional for concerns that she may be experiencing? Obviously, support groups can play a wonderful role, Post-Treatment Resource programs I'm sure are very valuable, but at some point the fear of recurrence, anxiety surrounding life as a survivor can become overwhelming. Any guidelines for how to recognize when you might require the assistance or benefit from a healthcare professional?

**Linda Roberts:** That's a very good question. There's really no timeline, like Dr. Oratz was saying. It could be as soon as one day after you finish your radiation treatment, and we've had group members come to us at that point and come into our groups at that point. It's whenever you feel that -- all of the symptoms that I described. You feel that everyone's saying, "It's time to move on," and it's a little bit hard to move on.

What we say at Post-Treatment is that when you're going through the treatment and the therapy, you're going through the crisis and all your antennae are up: just what to do next, who to call next, where to go, what your appointment is, who is going to take you, who is going to take care of the kids. Then as soon as everything is over, that's sort of when your feelings come into play a little bit more. Things are a little bit calmer in terms of your time, and that's often when

the anxiety and depression can kick in and feeling the fear of recurrence and feeling a little bit overwhelmed. It's never too soon to call a health care professional. It's also never too soon to call the health care professional during treatment. That's a very important time to get some support. But in terms of after, with post-treatment, while you're finishing your radiation, while you're finishing your chemo, right after.

**Rochelle Shoretz:** Lisa, every day we read about some new supplement or product that has been identified as the new "cancer prevention miracle." How do we, as young survivors, identify those miracles that are actually worth heeding?

**Lisa Goldberg:** Basically, those few websites that I did mention, you can get accurate information. Sloan – Kettering has their website, mskcc.org, About Herbs. Again, the supplement industry is really not regulated by the FDA, so we don't know what we're getting within those products themselves.

The bottom line is the best thing is getting [nutrition] from your whole foods as opposed to taking a supplement. I'm just going to give an example. We did research a few years ago looking at vitamin C and breast cancer, and I'm sure during the cold and flu season many patients took vitamin C. What they found with vitamin C though -- and, by the way, vitamin C does not help the common cold, but what they found is that vitamin C actually gets incorporated into the cellular structure of the cancer cell as well and fuels it.

**Rochelle Shoretz:** I'm wondering if there might be some connection between the notion of massage and addressing peripheral neuropathy?

**Jill Dennis:** As far as massage, I would avoid any deep tissue massage, especially if it's very deep tissue. The reason being when you have deep tissue massage, it increases the amount of blood flow, which means increased lymph to that site, which means that you may have an overload for your lymphatic system. A good idea -- at Integrative Medicine, it's located on 65th Street, between 2nd and 3rd Avenue -- they offer massage specifically for all kinds of cancer patients, and they incorporate Swedish massage, all those different kinds of massage, and you can still get that massage and it won't affect you in any kind of way.

As far as peripheral neuropathy and occupational therapy, there is no real massage that you can do for peripheral neuropathy. But I did create my own little peripheral neuropathy pit at my job, which is a device to help you button your buttons, or we have Thera-Putty that comes in different strengths. You can actually get them online. You just type in Thera-Putty and it will come up with a whole kit to increase your strength and help you manipulate your fingers. If you continue to have problems, I would definitely get a consult on our out-patient services here at Cornell, so that we can assist you with those devices and keep you strong.

## IX. Symposium Conclusion

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**Rochelle Shoretz:** Thank you very much. As we wrap up this evening, please join me in thanking all of our speakers for generously sharing their time. I'd also like to thank our sponsors once again for bringing us all together -- UJA Federation of New York, Fertile Hope, Weill Medical College of Cornell University, and the Lance Armstrong Foundation.

Please be sure to complete the evaluation forms you've received. Your feedback is very, very important to us.

And thank you all for joining us this evening. The road toward survivorship -- however one defines that term -- can be at once exciting and perilous. Tonight, our panelists have shared their insights into this important journey, a journey shared by young women affected by breast cancer, their families, and the health care professionals who care for them. We look forward to continuing this important conversation with you all in the hopes that survivorship rates soar in the years ahead.

Good night.