

Young Women Facing Breast Cancer: What We Need To Know Now

Roundtable Discussion Transcript
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Presented By:



Linking Young Jewish Women in Their Fight Against Breast Cancer

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I. Introduction

Rochelle Shoretz: Good evening, everyone. I'm Rochelle Shoretz, the Founder and the Executive Director of Sharsheret. Welcome.

Thank you for being here as part of the first Medical Advisory Board roundtable at Sharsheret, entitled "Young Women Facing Breast Cancer: What We Need to Know Now." I'm particularly delighted to welcome you to Sharsheret's new headquarters here in Teaneck, New Jersey, and happy to welcome our participants across the country, who either e-mailed questions in advance or are reading the transcript of this event right now.

I want to start by thanking the North Jersey Affiliate of the Susan G. Komen Breast Cancer Foundation and Diane Siegel, who is with us tonight, if you could raise your hand so everybody knows who you are, for their very generous support that enabled us to present this evening's symposium. And I want to introduce Sharsheret's staff, many of whom you've spoken with on the phone but don't always have the pleasure of meeting, who are here with us tonight. If you can raise your hand or stand up when I call your name that would be wonderful. Elana Silber, our Program Director; Ellen Kleinhaus, our Program Coordinator; Shera Dubitsky, our Link Program Coordinator; and Sari Stein, who I think is still outside, she's our Sema Heller intern for the summer. So, thank you all for all of your hard work in putting this together. And thank you to the members of our Medical Advisory Board, who you will meet shortly, for your efforts tonight and your continued support of Sharsheret over the years.

Tonight is about the women of Sharsheret, the concerns we face as young women with the breast cancer, the treatments we elect, and the research that will hopefully save lives. Each member of our distinguished Medical Advisory Board will introduce themselves, speak for approximately 3 to 5 minutes on some of the concerns of very young patients, and then open up for questions. Our hope is that tonight really will be an informal opportunity for all of us to ask the questions that are foremost on our minds and to hear from you all the views of the health care profession in terms of the cutting edge of practice for young women facing breast cancer.

With no further remarks from me, thank you all for participating, and Dr. Oratz, perhaps we can start with you. Could you tell us a little bit about yourself and then some of the concerns you see in young women?

II. Presentation by Ruth Oratz, M.D.

Dr. Ruth Oratz: Thank you, Rochelle. I'm Ruth Oratz. I'm a medical oncologist and I have a private practice in New York City, affiliated with New York University School of Medicine, and I take care of women of all ages and with all stages of breast cancer. Tonight we're focusing on young women. I see women who have breast cancer newly diagnosed, I take care of women at risk, who may not have a diagnosis of cancer, but either because of a personal history or a family history may be at increased risk, and I see my patients through all stages of disease, even if their cancer recurs and they develop metastases, of course I take care of them.

I think that our concerns as physicians taking care of patients with cancer are very often focused on the immediacy of treatment. What should the treatment plan be now? And as a medical oncologist, I'm involved in planning around systemic therapy, chemotherapy, hormonal therapy, and now the new biologic agents. We're conducting a number of clinical trials in the office, and that's a very important component of cancer treatment, especially breast cancer treatment. It is through the good graces of women who agree to participate in clinical trials that we will answer important questions about what are the best treatments for each stage of disease and for each type of breast cancer, because, as you know, breast cancer is not just a single disease but comes in lots of different versions.

That seems to be our immediate focus, is always on the medical plan, but really some of the biggest concerns and some of the most important questions are not what happens during treatment but what happens once treatment is finished and how that woman is going to then, after she's gotten through all of those immediate side effects of treatment, regroup, put herself back together, re-enter her life as a woman in her family, in her community, in her work at home, in her work outside of the home, how she feels about herself as a woman, if she's single, if she's in a relationship, how she reintegrates into that world that she was in before she was diagnosed with breast cancer. And that has become increasingly an important focus in my own practice and I think in the medical oncology world. We'll be talking about that, I think, tonight as we address some of these other issues.

III. Presentation by Elsa Reich, MS, CGC

Elsa Reich: I'm Elsa Reich. I'm at New York University School of Medicine in the Human Genetics Program. And for the last 10 years, I've been providing genetic consultation and testing for women who are concerned about an inherited predisposition to cancer. And one of the things I can't emphasize enough to women, whether they be young women or whether they may be somewhat older, is importance of the family history. And I think it's very important that we all, as patients, as professionals, and as members of this society, talk about our family history, that we ask our parents about the family history, and that we, as parents, tell our children about the family history. Because it's through knowing about the family history that we can better provide an accurate assessment risk to our patients. And I know that within some families and in between generations, it's not always an easy thing to talk about what's going on in the family. I can only encourage all of you to encourage your family to talk about it.

And another thing that I would like to talk about is one of the most difficult things for me is when I have an individual coming to me because his or her doctor has told them that it would be a useful thing to have genetic testing. And they report to me that one or more of their friends or relatives had said to them, "Well, why do you want to do that? What good is it going to do you?" And I'd like to say that there are real benefits to having genetic testing. Not everybody has to have genetic testing, and it is an elective process. And so when someone comes to see me, they don't have any responsibility to make me happy. They only have a responsibility to make themselves happy.

But I would like to just comment briefly on what some of the benefits of testing might be. And I think of it as there being three main reasons that people elect to have testing or think about having testing. One is that it may very significantly influence their medical care, whether it be surveillance, whether it be risk-reducing surgery, whatever it might be. That can be a very important issue, the importance and the utility to the individual.

Secondly, there can be a utility for other family members. And that sometimes can be an issue because it's not uncommon that people tell me that their parent, their sister, their brother, their cousins don't know that they have breast cancer, or there are estrangements within the family, and it's always difficult when that occurs. Sometimes people are not willing to do it on behalf of their relatives, and sometimes for a young woman or an older woman, who herself has not had cancer, my recommendation is if there is an affected individual in the family who would be willing to have testing, that would be the optimal way of proceeding. And unfortunately, that doesn't always happen.

Lastly, there are many people who want to have the testing, just to know, because sometimes the anxiety of not knowing is less than the anxiety of knowing. I'll say it the other way around - the anxiety of knowing is less than the anxiety of not knowing. And it's always an anxiety-provoking situation, because genetic testing is not like having your tooth pulled. And when I see a patient in my office, I see the patient's family dotted in the shadows around her, because I consider, as many geneticists and genetic counselors do, that the family is my patient. I think beyond the given individual, and that sometimes is helpful to that individual and sometimes not.

One last thing I would like to comment about is that I many times have individuals, and mostly I would say women of a certain age, as they say, who tell me that they're having genetic testing on behalf of their children, particularly their daughters, and I always ask, and does your daughter know that you're having genetic testing? And I would say many times, I won't tell you more times than not, but many times the woman will say to me, well, I'll tell her when I've had my testing. I always encourage her to tell her children, her relatives, before she has the testing, or at least at the time that she has the testing, so that they can come to a conclusion on their own about whether that's information they want or not, so that they, too, can have their own autonomy in making a decision about genetic testing. And I've had many women tell me after the fact how grateful they were that they had told their children or their sisters.

I haven't talked about the real genetics of testing for breast cancer, but I want us all to think about some of the issues that are involved in genetic testing, because to me they are just as important as the actual medical importance.

IV. Presentation by Thomas Kolb, M.D.

Dr. Thomas Kolb: My name is Tom Kolb and I'm a diagnostic radiologist, specializing in breast cancer detection, generally in young high-risk women. And I was involved in some of the earliest trials that defined the sensitivity of mammography and physical examination, that is how often mammograms and physical examination found or did not find breast cancer that was present, by using ancillary tests, such as ultrasound in that particular case and that particular research endeavor.

And we've gone from just a scan two years ago from doing a single mammogram once a year on patients. And I should say that mammography still is the only screening examination that has a proven mortality benefit. In other words, just because we're doing additional testing that we will talk about, we should not forget that mammography is still the only test that has been proven to save lives to this point. But we've gone from where we generally had a single method for detecting breast cancer as a screening test, that is one mammogram a year for all women, regardless of risk, to where now we're carrying our examinations to different types of women, to different breast types, whether the breasts are fatty where cancers have been more easily found on mammography against where they are less likely to be found on mammography, and that is in women with very dense breasts. Up to 58% of breast cancer isn't seen on mammography. To where now we're carrying our examination to women that are high risk or normal risk would be for detecting breast cancer.

And we've gotten to a point now where I believe that we're now doing mammography once a year. But in conjunction to that a second test, such as ultrasound, if the woman does have dense breasts. And if she is a high-risk patient, we're adding on secondary testing at 6-month intervals, in between the two mammographic examinations, with either an ultrasound or an MRI examination. And by doing this, we're hopefully finding cancers at an earlier stage and saving lives. That yet still needs to be proven.

There is no question that these ancillary tests - ultrasound and MRI - can find cancers where mammography and certainly physical examination fail. We still need to do additional testing and there is a national multi-center study ongoing to test portions of the abilities of these tests to impact on patient care. So we've gone from a single thought screening examination to a more tailored examination in a very short number of years, and certainly that has been a major advance. Patients who come and speak to me certainly want to know what's available out there, what tests should they have, what new tests are there, and when they should have these tests. Maybe that would be something that we can talk about as the conference continues.

V. Presentation by Allison Rosen, M.D.

Dr. Allison Rosen: Hi, my name is Allison Rosen and I'm in private practice and I work for American Fertility Services and my goal and passion in life is to help anyone who wants to become a parent become a parent. And to that end, I founded the Fertility Preservation Special Interest Group, along with a man named Kutluk Oktay at Cornell Medical Center, called the Fertility Preservation Special Interest Group, bringing together cancer specialists and fertility specialists to work in helping people preserve fertility. In addition, I try and help patients negotiate the world of adoption and the world of reproductive medicine. They are both different cultures and they're often times very difficult to get through. One thing I want to mention is that you can become a parent through adoption, but the adoptive world does discriminate against cancer survivors and you need to have information and you need to know that.

As you may know, a lot of times cancer specialists, none of the people here, but around the country, not in the top-notch places, don't always tell cancer patients that their reproductive potential may be harmed or that it may be shortened. And patients don't have adequate information and resources because the physicians don't have adequate information and resources. I work with Fertile Hope. I'm on their medical advisory board and Resolve, I'm the former Executive Director of Resolve, which is an infertility group, to help patients try and get information and to disseminate the information amongst the reproductive world and the cancer world.

VI. Presentation by Gila Leiter, M.D.

Dr. Gila Leiter: I'm Gila Leiter. I'm in private practice in Manhattan in OB/GYN. I'm also an attending in Mt. Sinai Hospital and teach in the medical school.

I spend a lot of time taking care of the gynecological health of women with breast cancer. Certainly when a woman is diagnosed with breast cancer there are a lot of gynecological issues that come up. Frequently, if it's a young woman, she still might be having her periods. She might still be ovulating at the beginning of her treatment. She requires contraception, and there are a lot of questions about that. She might be experiencing irregular bleeding and so she needs definitely to be counseled and have a good resource. Lots of issues with treatment, such as the Tamoxifen and irregular bleeding, certainly in a pre-menopausal woman, come up.

Also, a big issue that comes up all the time is a young woman who is experiencing irregular periods while she's undergoing chemotherapy and then getting hot flashes and not knowing what to do about it and how to treat it and what's safe, what's not safe. Frequently, women will use alternative medicine and be afraid to speak to their physicians about it or to their oncologists. And it's important always to counsel a woman, please tell me what you're taking, how that might affect your treatment, and certainly there are some treatments that might be safe and might be helpful and get her through a difficult time.

Lots of questions about body image come up, either because of surgery or because of treatments. Or frequently a young woman, who is no longer having her period, wants to understand when she will get her period back, if she will get her period back, what, in fact, is her fertility, as you alluded to, and that certainly is a huge issue.

And then a very large area is sexual health. A lot of women experience vaginal dryness, vaginal pain with intercourse, and so women need to be counseled and talked to about what to expect, how to treat it, if there are safe treatments for a breast cancer patient.

And then, of course, I take care of many, many families with multiple generations of women. And so, of course, screening various members of their family, as well as, importantly, the young woman with breast cancer, to see if she, in fact, is at risk or carrying BRCA1, BRCA2, how that affects all the various members of the family. And frequently even young members in the family. I get, frequently, young women in my office, 17, 18, who are afraid to use oral contraception because mom had breast cancer. These issues really affect entire families, not just one person, when a diagnosis of breast cancer is made.

VIII. Presentation by Sheldon Feldman, M.D.

Dr. Sheldon Feldman: Hi, my name is Shelly Feldman. I'm a breast cancer surgeon and I'm Chief of the Breast Cancer Program at Beth Israel Medical Center in Manhattan.

I've been involved in the breast cancer world really my whole career, starting with my sister's illness when I was a resident 26 years ago, and sort of experienced the breast cancer experience. Although I didn't have breast cancer, my sister did. I began to see a lot of the experiences that breast cancer patients go through through her eyes, and it certainly was educational for me, and continues to be so.

I've been involved in trying to develop some minimally invasive approaches surgically to treat breast cancer. It started in the mid-90s with channel node biopsy, which, in turn, has become an important advance. We've been involved in using endoscopic approaches now to do breast cancer surgery and also beginning to develop techniques of what we call the intraductal approach to treating breast cancer, which is actually treating the lining of the milk ducts directly. We have small endoscopes, which have been devised to get a look at where the breast cancers begin.

I'm very interested in environmental factors, as they relate to the development of breast cancer. And certainly, as some of the other speakers have alluded to, the whole concept of genetic testing as it relates to breast cancer. One of my own personal crusades, I guess, has been with the Sharsheret community a bit, sort of having lively discussions with some of our Rabbis about the pros and cons of genetic testing, if they want to do testing, which I believe is very, very important powerful information for the appropriate patient to get for her and her family.

As you know Ashkenazi Jewish women are a high-risk group, with large families, many women at risk. And we see many patients who come into Beth Israel with very big family histories with many women with breast cancer, who come in with advanced disease because they have never been screened because there was never any discussion and it was a secret and nobody wants us to know. And that's painful to see that when this information potentially could be able to change that.

As Dr. Kolb alluded to, we have, they're not perfect, but we have very good surveillance technologies available and new ones being devised all the time. I think that's an ongoing educational effort, to try to come into line with some of the rabbinical leaders about the importance of genetic testing.

And I'm pleased to be here with you tonight.

VIII. Question and Answer Session

Shera Dubitsky: Thank you very much for those introductions. I'd like to open it up to some of the women who are here, if there is anybody who has a particular question. Maybe I'll start with a question. I'm going to address this to Dr. Kolb. How effective are mammograms in young women after a mastectomy?

Dr. Thomas Kolb: Well, after a mastectomy, we still have an unaffected breast and so there are a couple of issues. If the breast is truly unaffected, we then are left with what type of breast it is, as I alluded to earlier. If the breast is fatty, in other words, there is not a lot of fiber or granular tissue, there is a lot of fat, and that really depends on the mammographic appearance, not on physical examination. If it is a fatty breast, then mammograms are excellent. Mammograms will find 98% of all breast cancer. The density of a breast is more likely a mammogram will not find breast cancer, up to a very dense breast, in which mammograms will not find 58% of breast cancer. And those women do resort to secondary screening methods in order to detect what mammograms may miss. That directly answers that question, but there are other screening methods we can talk about as well.

Shera Dubitsky: And who would be recommending that?

Dr. Thomas Kolb: It's really the radiologist who decides how dense a breast is. You can't tell by physical examination, by the firmness or softness of the breast, whether the breast is large or not. It really is not dependent on physical examination. It really isn't diagnosable by physical examination, but by the appearance of the mammogram. Mammograms are black and white. The dark areas are fat, the white areas are glandular tissue. The fattier the breast, the more dark it is on a mammogram. The more dense it is, the more white.

And there is an American College of Radiology grading system, which grades breasts from Grade 1, which is fatty, to Grade 4, which is the highest grade density breast. The information is available from the radiologist and now actually from my earlier publication, the ACR, the American College of Radiology, who set up the grading system from 1 through 4, knew that there was a problem in detecting breast cancer in women with dense breasts, but they didn't know what the numbers were. Our study actually defined how often these cancers were being found or being missed mammographically. It's the radiologist who has this information that can suggest other testing which may be helpful.

Shera Dubitsky: And on the heels of that question, I guess I'm going to ask for a repeat performance, Dr. Oratz, because I think that you had actually answered this question at a previous symposium. The question is who takes the helm?

Who makes the decisions once somebody has finished treatment? Who is sort of guiding the woman along beyond that? Is the woman continuing to see the radiologist? The oncologist? If you can, perhaps, re-address that.

Dr. Ruth Oratz: I am very bossy by nature, so I would like to say that -- but actually there really has to be a team approach and I have the good fortune of working with everyone at this table as part of the team in taking care of patients. And I think Dr. Kolb really highlighted, for example, when it comes to the question of how to best image the breast tissue, I rely on the radiologist to give guidance there because that's really the person who is looking at the image and then looking at the patient and putting that all together. For a woman who has a history of breast cancer, she really needs to see everyone on that team. The diagnostic radiologist is following her for surveillance, whether she's had a mastectomy with reconstruction, whether she's had a lumpectomy followed by radiation therapy, she still needs to be seen and followed. That may include mammography, maybe ultrasound, maybe MRI. And if the radiologist makes a strong recommendation, I think that that's an important part of that team effort.

The patient is also followed by her surgeon after a diagnosis of breast cancer. The surgeon knows what he did, which he did in the operating room. And physical examination is still a very, very important part of follow-up for the woman who has had surgery for breast cancer or even for a benign but perhaps pre-cancerous breast lesion or a non-invasive breast lesion. The radiologist and the surgeon work very, very closely together if there is a physical finding in coming up with the appropriate approach in order to make that diagnosis.

As a medical oncologist, I coordinate the systemic therapy of that patient, the after effects of chemotherapy, if she's gone through chemotherapy treatment, hormonal therapy, and biologic therapy. And then there are things that happen to people's bodies when they go through this treatment. I'm also interested in bone health, for example. We know bone density is affected. We know that the cholesterol levels and the lipid levels can be affected by treatment. We know that thyroid function can be affected by treatment. As the medical internist involved in caring for a patient, both in formulating her treatment plan and her after care, I supervise that general medical care.

Elsa and the team from the Genetic Counseling Department, of course, are very involved in counseling our patients who are at risk for genetic susceptibility to breast cancer and they play a very important role, not only in determining if the patient should be tested but in counseling those patients and their families and following up with them after testing has been done. As Dr. Leiter said, the gynecologic health of a woman who's had a history of breast cancer is immeasurably important, not only for all of the issues that she detailed in her presentation, but women who have a history of breast cancer, whether or not they have a BRCA mutation, may be at risk for other malignancies - ovarian

cancer or uterine cancer, endometrial cancer - and also need to be examined very carefully as well and have surveillance for that.

And then finally, the issue of fertility can't be neglected, particularly in the young patient. This really is a team approach. And I think we all like to feel that we are the captain of that ship, but we're all on that ship together.

Shera Dubitsky: Okay. I'd like to open it up to the floor.

Unidentified Participant: After you go through and you've seen everybody and everybody has done everything and they say, okay, you can go on now. When you have an issue, who makes that decision as to who you go to? Do I make that decision and say, okay, this is what I think it is and I'll go to this doctor, and if it's not, I guess they'll redirect me or I'll redirect myself? Or do I call one person in particular who will take the helm and then they will direct me?

Dr. Ruth Oratz: I think it depends on what the nature of the question is. If it's a very sort of general question, you could start, I would say, either with the surgeon or the medical oncologist, and that would be sort of the kind of general practitioner who is overseeing your specific case. If it's a question specifically about surveillance, when should I have my sonogram or my mammogram, your surgeon or your medical oncologist could give you guidance. Certainly you could call the radiologist as well. And again, obviously, if it's a specific gynecologic question, you might turn to the gynecologist.

Now, very often, we'll see a patient and say you need your bone density or you need your colonoscopy and they'll hear that from any one of a number of your medical practitioners. I don't know that you're locked in necessarily to one or the other. It may just be the next person you have an appointment with. And we do actually speak to one another.

Unidentified Participant: Okay. And just one of -- I'm sorry. If you don't mind. You mentioned the bone density, you mentioned a question on thyroid issues. Where do they come up in terms of what treatment -- what treatment affects those areas?

Dr. Ruth Oratz: That's a very specific question. I'm not sure we have time to go into all of those details, but I will just say, in general, because we are focusing on young women, when the treatment moves a woman from a pre-menopausal state to a post-menopausal state, whether that's chemically through medications or surgically because we've manipulated something, like removing the ovaries, that's when we see the biggest changes metabolically in the body in terms of bone density, the cholesterol, with the profile, and some of these other factors.

Unidentified Participant: I have a question about not being diagnosed in a younger woman whose mom just had breast cancer. And my understanding as of now is that really there is no good tool to diagnosing and really starting to screen young women. Now, I know that if your mother was diagnosed at 41, theoretically you should have your first mammography at 31, but I hear that that's not really a good tool, mammography for a 31-year-old necessarily.

Dr. Thomas Kolb: We have a number of tools. You are going to see the Achilles' heel of mammography, as we've talked about, occurs in younger women, two-thirds of pre-menopausal women have dense breasts, and that's where the problem lies. But now we have ultrasound and MRI and those tests are very good at finding cancers. MRI will find 6 to 8% more cancer than the ultrasound/mammography combination. It's still 6 to 8%, but there are pros and cons to every test. But just to answer, as a generalized answer, we do have tests that are available to younger women these days that weren't available 10 years ago that do work.

Unidentified Participant: When you say screening for a 31-year-old, do you recommend an ultrasound with mammography?

Dr. Thomas Kolb: A 31-year-old with an increased risk of subsequently developing breast cancer, either because of her primary family member or a personal history of breast cancer or a precancerous, so to speak, lesion that was previously diagnosed, I would do a mammogram, and if she's dense, add an ultrasound to it, six months later I would do either an ultrasound or an MRI, a screening ultrasound of both breasts or a bilateral breast MRI, looking at both breasts at the same time. There are pros and cons to both approaches. You will find the vast majority of all detectable cancer with using those tests at the age of 31, even with dense breasts. There are new techniques and technologies coming out. They are still being tested. I tested a number of them. Nothing yet is out there for the consumer. Nothing has been published and researched well enough to show any benefit over what I've just said about my particular scheme. But there are tests available where a 31-year-old can feel relatively comfortable that she does not have detectable breast cancer.

Unidentified Participant: After the initial screening, base-line screening at 31, does that person get screened every year?

Dr. Thomas Kolb: I start screening mammographically 10 to 15 years prior to the primary family member having breast cancer. I don't start mammograms younger than 25 to 27. I will do ultrasounds in women that are younger -- or MRIs in women that are younger than 25. But I will do mammograms annually in women above 25 to 27 with a strong family history.

Unidentified Participant: Okay. And then the MRI. It's been my understanding that everybody who has breast cancer should have an MRI. Anybody who has been diagnosed should have it. How often after that would you recommend having the MRI?

Dr. Thomas Kolb: You should know that that's not universally accepted. We're in an area now where it's evolving. The reason to do screening -- to do an MRI at the staging, when you've just been diagnosed, somebody has just been diagnosed with breast cancer - is to see whether there is additional disease in the breast that's affected or disease on a contralateral, the opposite side, so that when a surgeon goes in and operates they have an idea of how extensive the surgery has to be. We do a staging MRI. You can do a staging ultrasound as well. It's becoming more commonplace. There are -- it's not as simple as it sounds though because radiation is generally given -- when women have lumpectomies, they receive radiation. And the reason for getting radiation to the entire breast, if there were other far-side cancer, we know from studies, from pathology studies on the specimen that there are 15% additional far-side cancer there. It's the radiation that takes care of that. Finding those additional far sides may help decrease the occurrence and guide the surgeon. But some people believe they were just upstaging women unnecessarily. It's not quite as simple as that, but a lot of people are now doing staging MRIs prior to definitive surgical intervention.

Shera Dubitsky: Dr. Feldman, you wanted to add?

Dr. Sheldon Feldman: Just one comment on the situation. I think that more and more though, again, we talk about breast cancer like it's one disease and it presents in so many different ways. And also, the first question you asked about screening for women whose mother had breast cancer, to me speaks to the issue of risk stratification, because there are -- some of those are women who may be BRCA1 or 2 positive, that would open the door to a very different -- [change tape]

Dr. Sheldon Feldman: But I'm saying the intensity of the surveillance for that high-risk woman, who is very high risk, would be different than let's say someone whose mother was diagnosed at 65. Although her risk is increased statistically, the jump is not so great and maybe her mammographic density is not so significant that maybe additional screening is not so important. It's very individual.

Unidentified Participant: Everything has to be individually focused.

Dr. Sheldon Feldman: Even with MRI screening for whoever has been diagnosed with breast cancer. I mean, the group that I worry most about are women who are mammographically occult. I mean, they know it's a lump and it's

not seen on mammography, and some of them are not seen on sonography, and when you think about follow-ups, surveillance for those patients, it's a little scary, as opposed to someone who has a small cluster of microcalcifications found, has an early DCIS or Stage I breast cancer found, a very good prognosis, that was picked up on routine screening. For her, perhaps, and it's not wrong to consider an MRI, but perhaps this routine screening really is all that she needs. So each situation, I think, is pretty individual.

Dr. Thomas Kolb: It's also important to remember that that same 31-year-old, if she's getting annual MRI screening, might end up with a lot of false positives and difficult biopsies, or MRI-guided biopsies. It's quite a nightmare. You always have to weigh the situation. Maybe risk stratification is a good way.

Dr. Sheldon Feldman: I'll tell you the way I approach MRIs, because that's a very important point. The MRI is now prevalent and we now talk about [it]. And that is I tell the patients the numbers and how often MRIs find it and then weigh it out with her. The false positive rate is very high. And you get onto this MRI cycle where you either come back in 6 months, get another MRI, or it gets a biopsy and it's not cancer. It is a very sensitive test, but it's not specific enough to differentiate benign from malignant, so we biopsy. We follow. And it depends on the woman's personality. There are women out there who want to know everything all the time right away. Those women would really benefit by having an MRI - whatever it tells you, even with false positives. They are motivated. There are other women, who, maybe not in this room, but they [don't want to do] everything, and ultrasound, usually it finds 90%, they'll go that route. And so I individualize that as well by talking to the patient.

Shera Dubitsky: I'm going to jump in. Just on the heels of talking about some family history. Also, I'm wondering if you could address this question. It comes up in different variations. But a woman called and she said if, let's say mom had breast cancer or somebody on mom's side had breast cancer, and mom tests negative for the BRCA gene, does that automatically mean that the daughter is BRCA-negative, or does the daughter also need to be tested as well?

Elsa Reich: You are giving me partial information, I would say.

Shera Dubitsky: I know. I'm trying to find -- we get different variations. If one person tests, what are the implications?

Elsa Reich: Let me say the following thing. I look at the genetic testing in a variety of ways. First, I want to comment that mutations can be transmitted through both the female as well as the male line. Not having a mutation in one's mother, even if she had breast cancer, doesn't necessarily mean that there is no mutation in the family. It depends on this young woman's history. If she herself has had breast cancer and she's a young woman, under the age of 50, and her

mother has had cancer and is negative for the testing, whatever it has been chosen to do, because sometimes you can do more or less, let's put it that way, I would still recommend under most circumstances that she go ahead and have the genetic testing. Because if she inherited a mutation from her father, it's possible that in a sense it could be occult. He might -- the implications for him are different. It might be that there isn't anybody else affected in his family. So it depends on the age of the individual, the total family history. I think it's too easy to say if it's not in the mother, who was affected, there is no purpose in being tested.

Shera Dubitsky: Okay.

Elsa Reich: If she were unaffected, that's a whole different issue.

Shera Dubitsky: Okay. I'm just going to close up this piece in terms of the family question. And somebody submitted a question, "My daughter, who is 22 years old now, had a fibroadenoma removed at the age of 18. As a daughter of a DCIS patient, diagnosed at age 49, what should her breast health plan be like and who should she see first?" I think I'm going to ask maybe the medical oncologist to talk about that.

Dr. Ruth Oratz: I know this isn't a place to give recommendations about the treatment of individuals. And rather to talk more generally about what Dr. Feldman was saying, this is someone who should come in and be seen by a specialist, who is either a breast surgeon or a medical oncologist, to assess her risks, determine whether genetic counseling is appropriate, and then refer her to genetic counseling and possibly testing, and then to talk to the radiologist about what the best way to be -- to develop a surveillance program for her. Again, we would look for that team approach.

Shera Dubitsky: Right.

Unidentified Participant: I'm just 32 and I am a survivor. I just completed four more treatments this month. I have to say it was very -- it was easier than I expected. But at the same time, I still have very -- I'm very confused as to what is next. And I visited with my oncologist today and unfortunately my team, they don't even talk to each other, unless I ask them to do it. I say make sure that you talk to -- I happen to be seeing my surgeon tomorrow. It's one of those things that I'll be asking the same questions to each doctor and I'll get different answers from different doctors. Who do I believe? What should I do? I mean, my gynecologist has been out of the picture completely. It's just -- where do I go from here?

Dr. Ruth Oratz: Well, what are your specific questions?

Unidentified Participant: Well, I guess --

Dr. Ruth Oratz: Generally.

Unidentified Participant: Generally, it's kind of hard to explain when it comes to things because I -- there are so many little questions and so many -- I don't want to take everybody's time.

Dr. Ruth Oratz: I'm not talking about in such a personal way, but if there were some general pieces of information that you think would be important to you to move forward.

Shera Dubitsky: Dr. Leiter, you had a specific point?

Dr. Gila Leiter: I just thought that perhaps you need to establish a gatekeeper or find one person in this game who is comfortable, who's willing to be your leader of the home, whether it's the oncologist. It doesn't sound like it's your gynecologist in this case or the breast surgeon. One person who you feel perhaps is more accessible, you have a relationship with, who you are comfortable with, and ask them to be in charge. You have a whole variety of things that need to be addressed, and I'm sure you're familiar with some of them. And plus your team should help you develop a protocol for surveillance of your breast, surveillance of your general health. And you have to find somebody who is willing to be in charge because that's important.

Dr. Ruth Oratz: And prioritize your questions.

Dr. Gila Leiter: Right.

Dr. Ruth Oratz: What are the questions that need immediate attention? When is my next mammogram?

Dr. Gila Leiter: Right.

Dr. Ruth Oratz: Those are sort of one group of questions. Then there is the next set of questions, which is that whole "what next" thing.

Unidentified Participant: Right.

Dr. Ruth Oratz: And that, you may have to reach out, as Dr. Leiter is saying, to different members of the team to address different aspects of how those issues in your life will come back together. And then in due time it will fall into place.

Unidentified Participant: I had a problem with the very first topic you got into, concerning diagnostic testing following a mastectomy. I've got the bilateral

mastectomy. Besides from the physical exam, is there any further screening that you need?

Dr. Thomas Kolb: Even with reconstruction, we don't use a lot of diagnostic imaging. There is no routine screening. Even with reconstruction, where a physical [determination] you think would be harder to do. The vast majority of recurrences occur at the suture line. We can physically feel them. Not all of them, but the vast majority do. And we don't routinely screen all of these women for recurrences. Whether they have implants or tram flap for reconstruction or just inspecting the site, we don't have any routine screening protocols, and so we really rely on physical examination after bilateral mastectomy.

We could do MRIs and so forth for it. Obviously, mammography and ultrasound are very limited on the mastectomy site.

Unidentified Participant: Even MRIs are not used to screen?

Dr. Thomas Kolb: Well, there is no screening protocol for MRIs or even bone scans for the ribs underneath the chest, in the chest wall. There is no protocol because it's rare to find tumors in that fashion that wouldn't be palpable.

Dr. Ruth Oratz: Depends on the stage. There are some people who are getting prophylactic mastectomies and reconstruction. So searching their bones may not be appropriate.

Dr. Thomas Kolb: Absolutely. And we still don't even screen them. Prophylactic mastectomies are even made from the breast tissue left. Of course, you can feel in a very small percent breast cancer after a prophylactic mastectomy, but we don't screen those women either routinely.

Unidentified Participant: Dr. Leiter, a question for you. Women who are, specifically the young women who are taking Tamoxifen, and then who are at risk or are concerned about risk of women-related cancers generally, do you recommend that those young women continue to see the OB/GYN that they were seeing before they were diagnosed or do you think they should see someone who will -- like the gyno/oncologist, for example - who has experience particularly with women and ovarian cancer?

Dr. Gila Leiter: Well, there are specifically screening protocols in Tamoxifen in a pre-menopausal woman. Really if she's having regular periods and not having any dysfunctional bleeding she doesn't need any specific screening. She needs to go for her checkups; she needs to go for her pap smear, etc. Certainly if, in fact, she's a carrier of BRCA1, BRCA2, she would need her ovaries assessed, and a gynecologist who has transvaginal ultrasound in their office or can refer to a radiologist that they're comfortable with is certainly adequate to do that

screening for that. In fact, I don't think she needs to go to a gynecological oncologist. Sometimes they are hard to approach. And also, they may not need to be in that kind of surveillance protocol.

Unidentified Participant: But cancer would be the same though for women who are on Tamoxifen from a prophylactic standpoint, meaning women who tested positive for the gene versus -- as well as women after the diagnosis of breast cancer?

Dr. Gila Leiter: Well, if a woman is diagnosed with -- is carrying BRCA1, BRCA2, someone has to counsel her about risk reduction surgery and then establish a screening protocol with her, for what it's worth.

Unidentified Participant: And you're comfortable that that could be done by an OB/GYN? It doesn't necessarily need to be taken --

Dr. Gila Leiter: Yes, an OB/GYN is comfortable with -- sure, absolutely.

Shera Dubitsky: Dr. Rosen, we want to address this to you. We get phone calls from young Jewish women who are single, and I'm wondering if you can, perhaps, address the question of fertility for single women, some of the things that they may be facing, particularly around disclosure while dating I think for themselves after breast cancer treatment. I'm wondering if you have any thoughts about that.

Dr. Allison Rosen: Well, I guess my answer would depend upon the stage of treatment of the woman. If she's just been diagnosed, she can have an IVF procedure, which will harvest eggs, and she has to be adequately counseled about freezing her eggs. There are other techniques that can be done. After that, she has to be told -- I mean, obviously, it affects a young woman's identity. She faces the fact that she may not be able to have children or it's a question in every dating situation, and when and how does she disclose this fact. That's very difficult for young women. The donor egg is a real option, but not all women want to do donor egg. And a woman loses her genetic component and that's very painful to a lot of women. She has to be going the whole rest of her dating history with this knowledge in the back of her mind. It can profoundly affect her identity and can affect all aspects of her life.

I see a lot of women who get depressed at this point, especially if they weren't adequately told what would happen and that there were options that could have prevented this. There is an intolerance of regret that this could have been prevented if they had been adequately counseled in the first place, and an anger that women carry with them.

Once that woman gets married, she can do donor egg or she can enter into the world of adoption. The answer is a multi-faceted answer, depending upon stage of diagnosis.

Dr. Ruth Oratz: Also dependent upon age at the time of treatment. The younger a woman is, if she's exposed to chemotherapy drugs, the more likely she is to retain fertility. The older she is, the less likely she is to have fertility in the first place and then chemotherapy on top of that and hormonal therapy will further reduce the likelihood of preserving for someone.

Dr. Allison Rosen: Right. She also may get her fertility back, but have her reproductive life shortened, and she has to be told that.

Unidentified Speaker: Right.

Dr. Allison Rosen: There are many nuances to the question of fertility age - related, treatment-related. Patients also ask even more basic questions, like will I get my period back? When will these hot flashes stop? What can I do to stop them? Other than even longer-term issues, such as fertility, sometimes short term issues.

Unidentified Participant: This question is about that testing. I recently got my period back a couple of months ago and then I did -- I'm sorry for being so personal. But does this mean that I can have children or does this mean that it's still a possibility that I might not be able to?

Dr. Allison Rosen: Well, obviously, getting your period back means that you're probably starting to ovulate again. And so the question about whether you should conceive or have pregnancies really relates to what stage you were treated, what treatment you'll need. I mean, traditionally, people have been asked to wait 2 years after treatment to make sure that you don't have a recurrence before trying to have a baby. But that may be, depending on the age of the patient and what's their fertility status, it may not be necessary. Certainly issues, such as contraception, if in fact it's very important, if in fact this isn't the right time for you. And so this is something that you should talk about with your oncologist. Find out when it's safe for you to be able to conceive. Some tests that's had some limited usefulness in terms of predicting what your fertility status is based on hormonal levels, sometimes at the beginning of the cycle. And then more immediate issues as to if you are getting your period back, you may be ovulating and may be some contraception right now. And so the dust settles a little bit and you know where you're at in your treatment. Obviously, I don't know what your fertility chances are.

Shera Dubitsky: Dr. Oratz, what are the particular breast cancer markers that need to be checked on periodically after breast cancer?

Dr. Ruth Oratz: There is some follow-up of a woman who has been diagnosed with breast cancer. I think largely it depends on the stage at the time of diagnosis. That is, what is the risk of recurrence? The higher the risk of recurrence, the more carefully we tend to look at things, like markers in terms of keeping an eagle eye out for the possibility of recurrence. The lower the risk of recurrence, perhaps we can back off a little bit on the testing.

The standard recommendations, in fact, are history and physical examination. Really there is no national recommendation by any group, ASCO, American College of Surgeons, that we routinely do either scans or blood test markers. But, again, based on the risk of recurrence, individual patients may, in consultation with her treating physician, elect to have, in addition to history and physical, some of these other tests as part of her surveillance. But there are no routine recommendations for markers.

Shera Dubitsky: Dr. Leiter, we have some questions actually about ovarian cancer. On the heels of that question, what about ovarian cancer markers?

Dr. Gila Leiter: You know it's very interesting because everybody coming to my office these days are asking for the CA-125. It seems to be from the Internet to the e-mails that go out. Unfortunately, the transvaginal ultrasound and CA-125 testing, which is the only real available screening tools for ovarian cancer, are notoriously unreliable. CA-125 is only positive in 50% of Stage I ovarian cancers, which is a very low number. Now, if somebody, in fact, has CA-125 and it's elevated, has surgery, then it's an excellent tool, for follow for recurrences, etc. But as an independent screening test for low-risk patients, it's notoriously inaccurate. The other big problem with CA-125 is that in a pre-menopausal woman it has a tremendously high positive rate and it's elevated if you have your period; if you have a corpus luteal cyst, which is a normal part of the menstrual function; with a fibroid; with endometriosis it could be usually elevated. And so CA-125 is a screening test.

In low-risk patients, it's terrible. Unfortunately, even in high-risk cases, even in BRCA1, BRCA2 carriers, or even in patients who have strong family histories, it's just not excellent testing. And there have been recent studies to, again, show that CA-125 and transvaginal ultrasound, even the size of false-positive rates, it's elevated. Just not great screening tools. Hence, a lot of the push for talking about risk reduction surgery, taking out ovaries in very high-risk patients is one way of ensuring at least that ovarian cancer risk is reduced. Not eliminated, but reduced. The bottom line is that CA-125, we do it when a patient asks for it, but they really need to be counseled that there is a high false-positive rate. And unfortunately, a negative result doesn't reassure that you don't have ovary cancers.

Shera Dubitsky: And would that be different for women who, the screening for ovarian cancer, be different for women who already had an oophorectomy?

Dr. Gila Leiter: In women who have already had an oophorectomy, screening is difficult. You're looking for peritoneal cancers. And that really, other than increased abdominal fluid or ascites, is difficult to detect. Luckily, very low incidents, 1%, peritoneal cancers, but it's not zero. And so really a high index of suspicion looking for any changes on physical exam or on history is important.

Shera Dubitsky: Dr. Feldman, we get phone calls about lymphedema. How do you determine your risk for lymphedema post surgery?

Dr. Sheldon Feldman: Well, statistically, a woman's risk of lymphedema is related to the number of lymph nodes that have been removed with their cancer surgery. There is a direct proportion. There are also some other factors which increase risk. For example, some women with more advanced disease, in addition to surgery, will also receive radiation to the lymphatic areas. For women, if 4 or more lymph nodes were involved typically, most radiation oncologists will recommend radiation to the supraclavicular lymph nodes, which are the upper lymph nodes, and that definitely does increase lymphedema risk.

Likewise, women who had mastectomy as part of their treatment, normally they would not be recommended to receive radiation, roughly have larger tumors or had 4 or more lymph nodes involved. That makes a clear correlation between radiation in addition to surgery and lymphedema.

With that being said, lymphedema is -- some of the precautions that we do recommend are helpful to decrease the risk, and certainly the management of lymphedema can be very successful. I think some of the things that we work with, occupational therapists and physical therapists, were protocols where many patients we now ask actually to meet with therapists preoperatively, knowing that their clinical situation is one where their risk for developing lymphedema is higher. By starting actually some range of motion exercises and their understanding the mechanics of the changes that may happen from the surgery that can be reduced.

We've also been working on a newer technique of doing lymph node surgery without making axillary incisions and actually doing the lymph node removal or biopsy through the lumpectomy incision. And we think that by avoiding the axillary incision there is less disruption of some of the lymphatics and that may reduce the risk.

Shera Dubitsky: We're going to be wrapping up. There was a question earlier, and I think it's in conjunction with another question that somebody had sent in about alternative therapies and nutrition and exercise. But there was a specific

question from somebody in our audience about soy and soybean oil, soybean lectin, soy sauce. I was wondering if anybody on the panel could address that question?

Dr. Ruth Oratz: I can start with the medical oncology because this is a systemic effect that we're talking about here. And the question really is a question about whether anything in diet or supplements has estrogenic activity, is acting like estrogen. And this comes from our understanding that many, but not all, breast cancers are promoted. The growth of the cancer is promoted by a high level of estrogen. About half of breast cancers in pre-menopausal women will express the estrogen receptor; perhaps in post-menopausal women, as many as two-thirds of breast cancers will be estrogen receptor positive. With that said, we, as part of our treatment, are often trying to reduce the level of circulating estrogen. That's one of the goals of treating estrogen receptor positive breast cancer. And we do that by using medicine, chemotherapy, hormonal therapy, removing the ovaries, setting down the signal for the ovaries, Tamoxifen, many, many different treatments that reduce the amount of estrogen.

What about adding pro-estrogenic drugs back into the system, whether that's through food or through simple supplements? You'd have to eat an awful lot of soy to really overcome the effect of Tamoxifen or Zoladex or oophorectomy. I mean really a lot. If you're eating tofu in your diet and you're ordering Chinese food once in a while or you're having some sushi and it has some soy sauce a couple of times a week, I don't think you're getting enough soy in your diet for that really to impact significantly what's going on.

If you're going out of your way to take lots and lots and lots of soy supplements, that may not be such a great thing. The data is controversial about this in terms of how much is safe, how much is in these supplements, and what you should take. In general, I counsel my patients that if they're having a normal portion in their diet a few times a week that's certainly safe. To take large amounts of supplements may or may not be safe. We really don't have data about that. It's probably safer to stay away from those very large amounts in supplements.

In terms of just general recommendations, there is some data that exercise and having a lower fat intake may be beneficial. Although the recent study that looked at the extreme low fat diet in breast cancer patients really did not show a significant reduction in the recurrence rate, we know that obesity is a risk factor for breast cancer, particularly in post-menopausal women. We do counsel patients, and I think for just general health it makes sense to have a moderate amount of exercise and a healthy diet of routine fruits and vegetables and natural nutrients and to try to limit the fat and sugar content of the diet.

Shera Dubitsky: Any other comments?

Unidentified Speaker: It's so interesting that countries [in which] there is a high intake of soy still have a lower rate of breast cancer. It's really worth bearing in mind.

Unidentified Speaker: In the diet, but not supplements.

Unidentified Speaker: Right. And estrogen has been used for hot flash control for ages without a lot of success. I think those in moderation --

Unidentified Speaker: You're probably correct.

Shera Dubitsky: Are there any other questions?

Unidentified Participant: I had metastatic breast cancer and there are lots of cousins and those relations that have one or the other. I did genetic testing. I tested for everything, all the BRCA genes, and then 2,700 other genes. And this is in Indiana. And the genetic counselor and the doctor, everyone was surprised because of my family history. And so I said, so what's the conclusion and he said, well, you may not have found your mutation yet. And so I wanted to know a little more about that. Because I've heard that --

Elsa Reich: I would say -- I think there are a couple of things to say. I think without having seen your family history, it sounds like there is a very significant possibility that there could be an inherited predisposition to breast and ovarian cancer. The testing, the most comprehensive testing, that is available in 2006 is not yet 100% sensitive, it's more like 85 to 90% sensitive. And there are some clinical trials, depending on what your family configuration is, whether there are people, enough people who are living to participate in clinical trials. It is possible that, in fact -- there is a possibility that some mutation could be found.

And in addition, probably by the end of the year, the common testing that's available now may be expanded somewhat because right now they're only looking for 5 very specific large rearrangements for deletions. By the end of the year, they are going to expand the methodology so that more of the rearrangements and deletions will be detected through the testing. And so I think that what I would do, if I were you, is either to go back, talk again with the genetic counselor in Indiana or speak to somebody closer to home here to find out whether there is a clinical trial that may be available to you. There has been some work that has been done. They haven't really found -- in the most recent study that was done there was no additional mutation found in any one Ashkenazi Jewish origin, although among non-Jewish individuals, who had undergone the full sequencing, as you probably had, about 12% of those individuals who fulfilled the criteria for participation had a previously undetected mutation.

I think that there is some future in keeping up with what's available now. When you are negative and you have a very strong family history, I would be very reluctant to say you don't have an inherited predisposition.

Unidentified Participant: That's what I thought, too.

Shera Dubitsky: Thank you very much. I will now hand over the reigns to Elana for closing remarks.

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X. Symposium Conclusion

Elana Silber: I want to thank every one of you for coming tonight. It's especially wonderful for Sharsheret because as a national organization, we don't generally get a chance to do a lot of face to face. Women speak to each other across the country on the telephone and the Medical Advisory Board doesn't get a chance to meet with the women of Sharsheret and their families. Here we have an intimate setting, we're actually talking face to face, this is very unique for Sharsheret. It is a tremendous accomplishment to get everyone together, open up to one another, and share information and experiences.

What we are doing at this event is videotaping thanks to the group back there. And we will be offering a copy of the DVD with the written transcript and the materials that were distributed this evening. And people here are able to share the information across the country.

And inside each folder there is an evaluation form that you can fill out tonight, if you can, or send it in tomorrow. It just was a very exciting week for everyone and I want to thank everyone for coming to our office, seeing where we are, come and visit every other day, for some people and then giving us an opportunity to bring everybody together continuing the Sharsheret, thank you.

X. Speakers' Bios

Dr. Sheldon Feldman is Division Chief of Breast Surgery and Chairman of the Committee on Cancer Activities at Beth Israel Medical Center. He has received numerous awards and recognition for his work, including "Physician of Distinction" by the American Cancer Society, Hudson Valley Region. Dr. Feldman has been listed in "The Best Doctors in New York" in *New York Magazine* and "Guide to America's Top Surgeons." His most current study, "Breast Cancer: Education, Counseling, and Adjustment," is a randomized clinical trial funded by a grant from the Susan G. Komen Breast Cancer Foundation.

Dr. Thomas Kolb is a radiologist in private practice in New York City specializing in the detection and diagnosis of breast cancer predominantly in premenopausal women and is also an Assistant Professor of Radiology at the Columbia University College of Physicians and Surgeons. Dr. Kolb was awarded Scientific Paper of the Year in 2002 by the American Medical Association for his publication in the *Journal of Radiology* analyzing and comparing the performance of screening mammography, physical examination, and ultrasound. Dr. Kolb is a member of numerous professional organizations and holds positions on several medical and advisory boards.

Dr. Gila Leiter is an Assistant Professor at the Mount Sinai School of Medicine and an Attending at the Mount Sinai Hospital. She maintains a private practice in New York City in obstetrics and gynecology. She is active in numerous professional societies and community boards. She is the author of *Everything You Need To Know To Have a Healthy Twin Pregnancy*, published by Random House, and has edited many books and articles on pregnancy and childbirth.

Dr. Ruth Oratz is Associate Professor of Clinical Medicine at the New York University School of Medicine. Dr. Oratz is the Founder and Director of The Women's Oncology & Wellness Practice in New York City and specializes in treating women with breast cancer and other malignancies, and those at risk for cancer. Dr. Oratz was named "Physician of the Year" by CancerCare in 2005. Dr. Oratz has been listed in "The Best Doctors in America" in *Redbook Magazine* and "The Best Doctors in NYC" in *New York Magazine*. Dr. Oratz is especially committed to helping the woman with cancer continue to live her life actively and fully, placing significant attention on flexible treatment programs that comprehensively address a woman's personal needs, including career, family life, and sexuality.

Elsa Reich, MS, CGC, is Professor of Pediatrics at New York University School of Medicine and provides care to children and adults with a wide variety of potentially heritable conditions. A significant fraction of her clinical practice of

genetic counseling is devoted to the care of individuals who are concerned about a hereditary predisposition to cancer. Ms. Reich has been an active board member of the New York Genetics Task Force, the National Society of Genetic Counselors, and the American Board of Genetic Counseling.

Dr. Allison Rosen co-founded the Fertility Preservation Special Interest Group of the American Society of Reproductive Medicine, where she currently serves as an officer of the Executive Committee. This group establishes policy, and provides education and research for preserving fertility. She is a Corresponding Editor to the Journal of the American Psychoanalytic Association and Contemporary Psychoanalysis. Her numerous publications about infertility include, *Facts and Fantasies in Infertility*, *In What do Mothers Want?*, and her most recent work, *Frozen Dreams: Psychodynamic Dimensions of Infertility Treatment and Assisted Reproduction*.

Rochelle Shoretz, Executive Director, founded Sharsheret in November 2001 while undergoing chemotherapy treatment for breast cancer at the age of 28. She has been named a Woman to Watch by *Jewish Women Magazine* and a Yoplait Champion in the Fight Against Breast Cancer by Yoplait, *Self Magazine*, and the Susan G. Komen Breast Cancer Foundation. Ms. Shoretz has lectured across the country, addressing issues facing young women with breast cancer. She has appeared on the Today Show and CBS News, and in more than 100 articles published online and in newspapers, including the *Wall Street Journal* and *USA Today*.

XI. About Sharsheret

Sharsheret is a national not-for-profit organization linking young Jewish women in their fight against breast cancer. Sharsheret (Hebrew for chain) pairs young women facing breast cancer with volunteers who can share their experiences, both personal and medical.

Sharsheret's programs respond to the needs of the women we serve and include:

- **The Link Program**, a peer support network connecting young women newly diagnosed or at high risk of developing breast cancer with others who share similar diagnoses and experiences.
- **Education and Outreach Programs**, including health care symposia addressing the concerns of young women facing breast cancer. Recent events addressed the subjects of breast cancer and fertility, parenting through breast cancer, breast cancer genetics, and surviving breast cancer. Transcripts of all symposia are available on Sharsheret's website, www.sharsheret.org.
- **Quality of Life Programs**, including the Busy Box for young parents facing breast cancer, Best Face Forward to address the cosmetic side effects of treatment, and Embrace, a support program for young women living with advanced breast cancer.

For more information about participating in Sharsheret's programs, please call toll-free (866) 474-2774. All phone calls are confidential.

Sharsheret is grateful for the generous support of:

The North Jersey Affiliate of the
Susan G. Komen Breast Cancer Foundation

XII. Disclaimer

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

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