

Taking Charge: Cancer Screening Updates Every Woman Needs to Know

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Presented by:



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Keith: Good evening, and welcome to today's program. At this time, all participants are in a listen-only mode. Later you'll have the opportunity to ask questions during the question and answer session. You may register to ask a question at any time by pressing star and 1 on your touch tone phone. You may withdraw yourself from the queue by pressing the pound key. Please note this call may be recorded. It's now my pleasure to turn the conference over to Shera Dubitsky. Please go ahead.

I. Introduction

Shera Dubitsky: Thank you, Keith. Thank all of you for joining us this evening as Sharsheret presents Taking Charge: Cancer Screening Updates Every Woman Needs to Know. My name is Shera Dubitsky, and I'm the Director of Navigation and Support Services. I'd like to begin by thanking BioMarin for their generous support in making this evening's program possible. We are delighted to welcome so many of you on tonight's call. Sharsheret is a national not-for-profit organization supporting young Jewish women and their families facing breast cancer. Our mission is to offer a community of support to women of all Jewish backgrounds diagnosed with breast cancer, or at an increased genetic risk, by fostering culturally relevant, individualized connections, with networks of peers and health professionals and related resources.

The media is flooded with stories about screening recommendations and guidelines that sometimes are confusing, or just contradict each other. We recognize that those of Ashkenazi Jewish descent, meaning those who have ancestors from Eastern Europe, experience heightened concern about these revised guidelines because of increased genetic risk. As many of you know, 1 in 345 individuals in the general population carry the BRCA mutation. For those individuals of Ashkenazi Jewish descent, that number is 1 in 40. This is astounding, and it bears repeating. Ashkenazi Jews are 10 times more likely to carry the BRCA mutation, resulting in as high as an 80% lifetime risk of being diagnosed with breast cancer, and as high as a 44% lifetime risk of being diagnosed with ovarian cancer.

Tonight's experts will walk us through the questions that you may have about how to be screened and how often, whether you are someone at a higher hereditary risk, or if you are a cancer survivor. Please keep in mind that the information shared this evening is a broad understanding of screening and related topics, and it should be really used as a springboard to discussions with your healthcare professionals.

I would like to now introduce our first speaker this evening, Dr. Lisa Weinstock. She's the director of Women's Digital Imaging of Ridgewood, New Jersey. She founded Women's Digital Imaging in 2004 to provide breast, pelvic, and bone imaging studies for women in a comfortable

environment, with immediate results to minimize anxiety. Dr. Weinstock has been specializing in breast imaging for over 18 years. She completed a fellowship in breast imaging at Columbia Presbyterian University Medical Center, and a 4-year residency in diagnostic radiology at Hackensack University Medical Center. She was an intern in the anatomic pathology of Montefiore Medical Center, and obtained her M.D. from the SUNY Health Sciences Center of Brooklyn. So without further ado, Dr. Weinstock, the floor is yours.

II. Screening and Monitoring for Breast Cancer

Dr. Lisa Weinstock: Thank you so much. I just would like to thank the whole Sharsheret community for giving me the opportunity to participate in this webinar tonight. My goal is basically to make some sense of all the breast imaging options.

As this cartoon demonstrates, there's a lot of confusing information out there. Every day another study seems to conflict with the recommendations of the day before. I just want to point out that top right. This is from the New England Journal of Panic-Inducing Gobbledygook.

Another cartoon. As this one demonstrates, the guidelines are at best confusing. Here's the doctor telling the patient, "You're suffering from confusing cancer guideline symptoms. We don't normally start testing for that until you're 30."

What are some of the challenges in breast cancer screening? First, benefit versus possible harms. What's worse, a missed cancer or a false positive? A false positive means that you're working up or biopsying something that turns out not to be a cancer. Very anxiety invoking. Now is every cancer we find going to progress and do harm? We have no way of knowing that at this time. There are many imaging options. None of them are perfect. That's basically what I'm going to be discussing tonight.

Sorting through some of the controversies out there. What is the best age to start screening? Do I need more than a mammogram? Is early detection too early?

Just a couple of interesting facts just on the bottom here. More than 250,000 women 40 and under in the United States are living with breast cancer. That's 1 out of 6 breast cancers occur in women between the ages of 40 and 49.

When should you start screening? What are the guidelines? Now, it's very important to keep in mind that these guidelines are for average-risk women, not for high-risk women. As Shera mentioned before, Ashkenazi Jewish descent in and of itself is considered a risk factor. Here are some of the basic guidelines. The American Cancer Society and the American College of Radiology recommends that mammography begin at age 40, not at age 50. In my opinion, consider a first baseline mammogram at 35, particularly if high risk. A general rule is to start screening approximately 10 years before your youngest first degree relative was diagnosed. So if your mother was diagnosed at age 35, you should start screening at 25. I think this may have been a Freudian slip here, but the cartoon went over the US Preventive Task Force recommendations, which basically states that screening mammograms should be every 2 years, biannually, between the ages of 50 and 74. This cartoon is basically leading women under 50 to their ultimate death.

Part of the reason that there are so many conflicting recommendations is that many of these recommendations are coming from different biased angles. Unfortunately, science in some ways is being replaced by an agenda. This cartoon, it's a little blurry, but it basically says that it takes 1,900 mammograms of women in their 40s to save 1 life, but only 1,300 of women in their 50s, so it's way more cost effective to only do mammograms in women in their 50s and older. That last gentleman in this cartoon on the task force says, "Just wait till you're 50 and stop calling us the Death Panel." The studies are trying to understand populations, not individuals. The policy recommendations are being suggested, knowing that cancers will be missed. So I think it's very important that each individual become their own advocate and know their own risk.

Here are some of the breast imaging modalities available to us. I will discuss most of these in further detail a little later. But mammography, tomosynthesis, 3D, all under the category of mammography. There's ultrasound, MRI, molecular imaging, which is synonymous with molecular breast imaging, nuclear medicine imaging. There's contrast enhanced mammography. Then just a couple of words about thermography. The reason I included it is because I think it's dangerous for women who are solely relying on this modality. There are some women out there that are refusing mammography and ultrasound and relying on thermography. We in the breast imaging world do not consider thermography a replacement or a supplemental test to mammography. It misses way too many cancers. The FDA came out with a statement to this effect in 2011.

First we'll discuss mammography. Mammography is the gold standard for screening worldwide. It's the only modality that has been proven over and over again to reduce breast cancer mortality if performed annually.

It's the best tool we have right now. This is mammography. It's not the only one that we need. It shows calcifications and abnormalities such as distortion of breast tissue, which we cannot see on other modalities. However, cancers can be difficult to see due to overlap of dense tissue, which I will get into a little later.

That brings us to tomosynthesis, which is synonymous with 3D. When patients hear 3D mammography, I think they're expecting a pop-up imaging to come out of the machine. No, it is not 3D in the way we think about 3D. It simply allows us to view the breast in thin slices. So it's basically like seeing the individual pages in a book and not looking through the book cover to cover. It's an upgraded, prettier mammogram. It's the newer technology. The downside is that there is still compression, and there's still radiation. In fact, the radiation dose really is an issue when it comes to tomosynthesis. With the newer software, it's the same amount of radiation when they do the tomosynthesis views. But until this point, what we call C-View tomosynthesis, has been double the amount of radiation. I think that tomosynthesis using the C-View, which is the low dose, is going to become standard, the standard mammography that is going to become available.

Now, one of the greatest benefits in tomosynthesis is that it reduces call backs. We all know about the call backs that you get from the imaging facility that you need additional views. Tomosynthesis eliminates a great majority of these call backs, and eliminates the anxiety, the aggravation, and the cost of returning for the additional views.

Here's an example of 3D and 2D images. As you can see, on the left this is 3D. You can see that tiny little nodule. It's well defined. You still see it on the right, the 2D, but you can't characterize it as well as you can the one on the left. This patient still needed an ultrasound. That turned out to just be a cyst. But you can see it's a much sharper image. Basically, I think tomosynthesis is an incremental step in the right direction, and I think this picture illustrates that. I don't think it's a giant leap in breast cancer diagnosis.

This cartoon I put in there just so that everybody understands that it's crucial, to understand that even with the newest, latest, and greatest technology, if the breast tissue is not on the image, a cancer could be missed. So please work with your mammo-technologist when they're positioning you. They're really not trying to torture you. They're just trying to get all your breast tissue onto the image.

When do you need more than a mammogram? Here are a few examples. If you have a personal history of breast cancer, strong family history, any of the genetic mutations, or the BRCA mutations. I'll also be discussing

later there are new mutations out there that are being diagnosed, if you have dense tissue, if you have a prior biopsy which shows a high risk lesion, or if you had radiation to the chest due to Hodgkin's lymphoma as a child.

What is breast density? Breast density is defined as the percentage of breast tissue versus fatty tissue within the breast. The problem is, tumors are white, cancers are white, breast tissue is white. So it's very difficult to find a cancer that's hidden in the dense tissue. Breast density has recently been proven to be a cancer risk in and of itself. Some studies are showing that patients with dense tissue have as much as a 4 to 6 times higher cancer risk compared to women with fatty tissue. As you'll see later, breast density and dense breasts, it's a spectrum. So when we're talking about these higher risk, these numbers of higher risk compared to fatty tissue, we're talking about the extremely, extremely dense tissue, and that's just about 10% of patients. Is it bad to have dense breast tissue? No. It's completely normal to have dense breast tissue. You just need to know that if you do have dense tissue, your mammogram may not be as sensitive or as helpful as someone who has fatty tissue.

A picture's worth a thousand words. So here are a lot of pictures. It's a little confusing. Okay, the bottom images are demonstrating breast density. Bottom left is showing fatty. Bottom right extremely dense. The ones in the middle are all in the spectrum of heterogeneously dense. Now, on the top left, that's a cancer in a woman who has fatty tissue. Easy to see on the mammogram. Easy to see on the next image on the ultrasound. The following, the yellow arrow on the top third image is showing a cancer easily visible in the ultrasound. On the ultrasound the surrounding breast tissue is white. The cancer is dark. It's clearly visible. That same patient, this is her mammogram, the yellow arrow is pointing to where the clip is. Where I put her clip is where the cancer is. There is some vague density there, but you would never have seen it on the mammogram itself.

The next image, top right, this woman came in, she felt this cancer, with a high-grade invasive cancer. Her mammogram is extremely dense on the bottom. You can't find it, not even on the tomosynthesis views. You cannot see her cancer. So that's basically demonstrating all the different varieties of breast tissue.

Depending on what state you're in, you may have recently received a letter or a comment about your breast density in addition to your mammogram results. I think it's up to 24 states now as of last week that have breast density notification laws. New Jersey has notification, just letting you know that you may have dense breasts. Pretty confusing. Why all this chaos? Dense breasts is not something new. We as radiologists

have put breast density into our reports to your doctors. The problem is that depending on where you went for your mammogram, you may not have known that you had dense tissue. The radiologist knew. The technologist knew. Your referring physician knew, but the patient did not know. The patient did not know that their mammogram may not be as sensitive in finding a cancer as, like I mentioned, somebody with fatty tissue.

A group of women whose cancers were missed on a mammogram, and whose cancers were found at a later stage formed an advocacy group called Are You Dense?. They went state from state trying to get this law passed that patients should be notified of their breast density. So that's what this is all about when you see on your letter telling you that you have dense tissue as well as your mammogram reports. It's important in order for you to be able to know that so you can discuss it with the radiologist, and with your clinician. I think on the next slide, or maybe it was the slide before, there's a great website that they formed called densebreast-info.org full of information about what to do if you do have dense breast tissue.

Okay, now I know I have dense tissue. What do I do? These are the different modalities in addition to mammography and 3D mammography. Ultrasound is a noninvasive test, extremely accessible, no radiation involved, no injections involved. It finds an additional 2 to 4 cancers per 1,000 women screened.

Here's an example of a cancer found. On the right, there's the cancer in the ultrasound, very clear. On the left, you can see a little metal clip in what we know is a cancer. This is a tomosynthesis view. We do not see the cancer on the tomosynthesis view.

I know what you're all thinking, because I get asked it every day. Why can't I just skip the mammogram? I have dense tissue. You can't see anything on it anyway. Why can't I just have ultrasound? The reason is, the mammogram is still the gold standard. There are certain things that we cannot see on ultrasound, such as calcification or subtle distortions. So even if your mammogram is not so sensitive, or let's say, 40% sensitive in finding a cancer and the ultrasound is 40% sensitive in finding a cancer, together they increase the sensitivity of finding a cancer. So they work together. You can't get out, at this time, of having a mammogram.

Just a few words on the physiologic modalities as a quick review. There's breast MRI and molecular imaging. As I mentioned, molecular imaging is the same as breast specific imaging. Many names. This gets very confusing. MRI looks at the vascular; the blood flow. Molecular imaging

looks at the cell metabolism. Mammogram and ultrasound look at the anatomy. So these are extremely sensitive tests. Of course, whenever you raise the sensitivity of finding a cancer, you also lower the specificity, meaning you're going to find things that aren't cancer. That is a problem with both of these tests. MRI has its drawbacks. They're on the slides, so I won't get into it. Of course, molecular imaging has its own drawbacks. But they're extremely sensitive tests. Here are a couple of examples.

These are cancers that have lit up on BSGI, which is molecular imaging. What's important here on the left is here you can see a cancer lighting up. To the extreme left is the mammogram. We see nothing. The next column you can see the cancer lighting up. Next column is a mammogram. Yes, we all see that cancer. The next column on the molecular imaging, you see the cancer, but the pink arrows are pointing to some activity that's going out from the cancer, meaning this changes surgical management. That cancer is not just what you're seeing, that round mass. The surgeon has to make a wider excision there.

Be careful of statistics. In my opinion, tomosynthesis is not a replacement, and I showed you examples for supplemental imaging. There was a lot of hype last year, it was all over the news, about this JAMA article that was claiming that tomosynthesis finds 41% more invasive cancers than standard mammography. That made no sense to me. After further investigation, looking into it, the formula that they used was kind of a skewed formula. So on this graph here, digital mammography finds 3 cancers, with tomosynthesis 4 cancers, which is per 1,000. Ultrasound found 6 cancers. So using the same formula, ultrasound finds 103% to 138% more cancers. It's important to know. If you go to MRI or molecular imaging, you're probably over 200% or more. It's important to note that the modalities work together to improve cancer detection. There is no breaking news about anything.

Individual risk assessment. I think we're going to be hearing a lot about this in that in general, in medicine in general it is crucial in the area of precision medicine.

Some conclusions on supplemental screening. For all women, I think digital mammography with tomosynthesis is going to become gold standard. For average-risk women who have heterogeneously dense tissue, or dense tissue, probably ultrasound in addition is a good idea. For patients who are low-to-intermediate-risk with dense tissue, consider ultrasound, possible MRI or molecular imaging. For higher-risk women, and by higher risk I mean family history or anyone who has a previous personal history of breast cancer, consider breast MRI or molecular imaging. Also just considering staggering your imaging studies in

intervals. We're trying to space them so that we can catch the interval cancers.

Okay, what can you do? Know your risks, your personal and family history. I don't think I have to say it to this group, but of course, the father's side is important, just as important as the mother's side. Know your breast density. Make sure to ask about supplemental imaging. I'm not going to talk much about genetic risk profile, but BRCA-negative diagnosis does not give you a free pass. I think it's important to know that there's new genetic testing that's now available called My Risk. We're now able to test for a whole slew of other genes that we weren't able to test for before, and I think we're going to find a lot of these genes in the moderate-risk families who've tested negative for the BRCA genes.

Here are just some of the modifiable and non-modifiable risk factors. I had to laugh when I was looking at this one. Gender was non-modifiable. I think we have to change that now, that that may be a modifiable risk. But there are things we can't change. Family history. In all seriousness, gender. There are things we can. Body fat. Physical activity.

In conclusion, remember, breast cancer is overwhelmingly a curable disease, particularly if found early. Even late stage cancers are kept under control with chemo and hormonal therapy. In order to find breast cancer early, we have to remember that breast cancer detection is a puzzle, and we need all the tools we have to put that puzzle together. Each modality adds to the picture. That's really it.

Shera Dubitsky: Great. Thank you very much, Dr. Weinstock. I found your discussion on dense breast screening actually particularly relevant as Sharsheret fields many calls from young women each year expressing concerns about screening and dense breasts. So thank you so much.

III. Screening and Monitoring Options for Ovarian Cancer

Shera Dubitsky: Our next speaker is Dr. Elizabeth Poynor. She is a gynecologic oncologist and advanced pelvic surgeon. Dr. Poynor's practice focuses on the care of the woman who is at elevated risk to develop cancer based on an abnormal pap smear, her personal medical history, or family history of cancer. She has special expertise in complex management of women and their families who have a genetic predisposition to developing breast cancer and gynecologic malignancies. Dr. Poynor also provides gynecologic care for women who currently have or have survived cancer, and may be experiencing side effects from prior or ongoing treatment. Dr. Poynor has co-authored numerous publications and book chapters on

topics in gynecology and gynecologic oncology, and has lectured nationally, internationally, and through the national media. She has appeared as an expert commentator on MSNBC, The Today Show, and WCBS. We are most proud to have Dr. Poynor on Sharsheret's Medical Advisory Board. So Dr. Poynor, the floor is yours.

Dr. Elizabeth Poynor: Thank you for allowing me to speak tonight, and hello to everybody.

This evening I'll be speaking about the screening options, and the challenges that we have for screening for women who are at risk for ovarian cancer.

Tonight I will be speaking about who is at elevated risk to develop cancer, what is the risk for these women who are at elevated risk, the challenge of early diagnosis of ovarian cancer, what are the screening techniques that we currently employ for the early diagnosis of ovarian cancer, who should be screened, the challenges with this type of screening, what are the options for risk reduction for women who are at elevated risk to develop the disease, and what's on the horizon, what are the new screening techniques and risk reduction strategies.

One out of 70 women will develop ovarian cancer in their lifetime. This is about a 1.6% chance of developing ovarian cancer in a woman's lifetime for the woman who is at average risk. It is the 5th most common cause of cancer death in women, and it is the leading cause of cancer death from gynecologic malignancies. Of the GYN malignancies, uterine cancer is the most common GYN malignancy. However, ovarian cancer remains the most lethal of these malignancies. Each year approximately 22,000 will be diagnosed with the disease, and unfortunately 15,000 women will die from ovarian cancer each year.

Risk factors for ovarian cancer include age, which is actually the greatest risk factor for ovarian cancer. All cancers are a disease of aging, so all cancers are due to accumulations of genetic mutations and environmental exposures, and as we age we develop more gene mutations and have had more environmental exposures. So actually the greatest risk factor to develop ovarian cancer is actually age. Reproductive history is also important. A woman who has more ovulatory cycles in her lifetime has a higher risk of developing ovarian cancer. An earlier age at her first period or later age of menopause, she will be at elevated risk to develop ovarian cancer. Surgical history, a woman who has had a bilateral tubal ligation has a lower risk of developing ovarian cancer. Not sure why this is. Maybe fewer environmental exposures or perhaps it disrupts the blood flow to the distal end of the Fallopian tube or the ovaries. But nonetheless, a bilateral tubal ligation will decrease a woman's risk of developing the disease. Oral contraceptives are protective against

ovarian cancer. A personal health history is also quite important. For some women with breast cancer, they'll be at elevated risk to develop ovarian cancer. Of course, as always, a family history, including inherited cancer gene mutations such as BRCA1 and BRCA2.

One out of 70 women will develop ovarian cancer in their lifetime. This is elevated perhaps if the woman has a personal history of breast cancer, a family history of breast cancer, a family history of ovarian cancer, BRCA1 and BRCA2 mutations, and also important to realize the Lynch mutations or HNPCC mutations are also important in developing ovarian cancer. Women who have numerous family members with colorectal cancer may also be at elevated risk of developing ovarian cancer. It's so important to know your family history of 3 generations. Of course, if a woman has a family history of breast and ovarian cancer, she's at elevated risk to develop ovarian cancer potentially.

So what are their actual risks to develop the disease? These can be categorized into a baseline risk or not that much higher than that 1 out of 70 risk, a moderate risk, and an elevated risk. Those who are at a baseline risk, we generally do not recommend ovarian cancer screening right now, as it stands outside of a research trial or study. Moderate risk women we recommend to have a discussion with a healthcare provider or an expert in cancer predisposition, and these women may opt to be screened. Women who are at high risk should be screened.

Women who are at population risk, or not that elevated over population, so a less than 3-fold elevated risk to develop ovarian cancer, include those women who have a history of breast cancer diagnosed at age 41 and older, who are not of Ashkenazi Jewish descent. So women who are of Ashkenazi Jewish descent, this actually is a little bit different, and these women may be at moderate risk to develop ovarian cancer. Women who are not of Ashkenazi Jewish descent and who are over 40 are at that baseline population risk to develop ovarian cancer in the absence of a family history of the disease, of breast or ovarian cancer.

If a woman has a history of infertility and has used assisted reproductive therapy, such as IVF, we still actually consider her at a baseline risk to develop the disease. The only fertility induction technology that has been really demonstrated to be linked to increasing the risk of ovarian cancer is actually the long-term use of Clomid, which people rarely do now. A history of endometriosis may increase your risk of developing ovarian cancer slightly, however, not significantly. A history of hormone replacement therapy after menopause may also increase a woman's risk to develop ovarian cancer slightly, but not significantly at this time. But stay tuned for more on this data. That data is emerging actually right now in the literature.

Women who are of moderate risk are that 3- to 6-fold elevated risk, who should have a discussion with their healthcare practitioner about screening, include women who have a first-degree relative, either a mother, sister, or daughter with ovarian cancer, have a personal history of breast cancer prior to the age of 40, or have a personal history of breast cancer prior to the age of 50 and have 1 or more close relatives with breast or ovarian cancer, those who have 2 or more close relatives diagnosed with breast cancer prior to the age of 50 or with an ovarian cancer diagnosis at any age. But these are what put you in this moderate risk category. Or, very importantly, women who are of Ashkenazi Jewish heritage and have a personal history of breast cancer prior to the age of 50 are considered of moderate risk to develop ovarian cancer in the absence of any genetic testing. Women who are of Ashkenazi Jewish heritage and have a first or second degree relative diagnosed with breast cancer prior to the age of 50, so no breast cancer, but you have a relative with breast cancer prior to the age of 50, or with a relative with ovarian cancer at age. It's so important to know your family history.

Women who are at significantly elevated risk to greater than 6-fold with an up to 50% risk of developing ovarian cancer include those who have a BRCA1 or BRCA2 mutation. Women who have a BRCA1 mutation have an up to 44% risk of developing ovarian cancer, and women with a BRCA2 mutation have about anywhere between a 15% and 25% risk of developing ovarian cancer. Of course, those women who have mismatch or paired gene mutation associated with Lynch syndrome, or HNPCC syndrome, and this one still goes unrecognized in some general practices. It's so important to know your colorectal cancer family history also.

Dr. Weinstock mentioned our newer genetic testing. We still know that about 15% of women who have a family history of breast and ovarian cancer, we can't find a genetic mutation which causes these cancers. However, we're now looking at what we call lesser penetrant genes. These are genes that, when you have a mutation, the risk of ovarian cancer or breast cancer may not be as high as that 44% chance of developing ovarian cancer with BRCA1, or 80% to 90% chance of developing breast cancer with BRCA1 or BRCA2. So a lower risk of developing cancer; however, they probably contribute to an important component of hereditary cancers. We're now starting to look for mutations in lesser penetrant genes such as CHEK2, RAD1, P53, and there's a whole laundry list of other genes which are being looked at.

So the panels that we're now looking at are the Myriad myRisk™. You'll hear people talking about this. This is a 23 to 25 gene panel. Ambry's Cancer Next panel actually is quite large and has, I believe it's 43 genes.

It's in the 40-gene range. Of course, academic institutions are developing their own panels.

What I'd like to do, for women who have a personal history of breast cancer, if they have no family history of breast or ovarian cancer with a diagnosis less than the age of 50, important to realize there's a possibly elevated risk of developing ovarian cancer. However, if a woman has a family history of breast cancer only, and a personal history of breast cancer, or a family history of breast cancer only, and she is BRCA1-2 negative, her risk of developing ovarian cancer actually may be back down to a baseline risk, because we know that about 50% of hereditary breast cancers are not associated with the BRCA1 or BRCA2 mutation. Some of these families, however, may be accounted for by mutations in these other lesser penetrant genes. So stay tuned for more, I think, on the future of that in terms of BRCA negative and you have a family history you really should review with somebody these larger genetic panels and how that would color your screening for ovarian cancer.

Of course, if a woman has a family history of breast and ovarian cancer and is BRCA1-2 negative, she may be a member of 1 of these 15% of families that are BRCA1-2 negative in this situation. However, she remains at significantly elevated risk to develop ovarian cancer. So important to always speak to a practitioner who understands that if you're BRCA negative you still may have an elevated risk of developing ovarian cancer.

The red flags for hereditary breast and ovarian cancer include breast cancer before the age of 50, ovarian cancer at any age, male breast cancer at any age in the family, multiple primary cancers or developing breast cancer twice, Ashkenazi Jewish ancestry, or of course, relatives with a BRCA mutation carrier.

The problem with ovarian cancer is that early diagnosis is quite difficult. The symptoms are subtle, and we still usually diagnose ovarian cancer at the most advanced stages.

Currently, only 24% of ovarian cancers are diagnosed at stage 1 where the tumor is confined to the ovary, and with any solid tumor with this early stage, the survival is quite excellent at 95%. The problem with ovarian cancer is the majority of cancers develop at stage 3 and stage 4, where the survival drops down to anywhere between 10% to 30%. So we really want to shift where we diagnosis individuals to stage 1, and that's where screening can help us.

Important to always know the early warning signs and symptoms of ovarian cancer, and this is important for any woman. These can be quite

subtle, and any woman can have these symptoms for a brief period of time. It's symptoms that are new and unusual for you that need to be reviewed with a practitioner, or symptoms that persist always need to be reviewed with a practitioner. These symptoms include a swollen or bloated abdomen, increasing abdominal girth, persistent pressure or pain in the abdomen or pelvis, difficulty eating or feeling full quickly, some subtle GI kind of symptoms. Urinary concerns such as urgency or frequency should always be reviewed with a healthcare practitioner. Change in bowel habits with new onset constipation or diarrhea, and unexplained vaginal bleeding sometimes can also be a presenting symptom of ovarian cancer, and always should be evaluated with an ultrasound. Any of these symptoms above that persist for a period of time should always be evaluated with an ultrasound and perhaps a CA-125.

The problem with screening for ovarian cancer is that once we're able to detect the tumor it's already spread, so it spreads quite quickly and quite subtly. There are limited preclinical phases to ovarian cancer. This is actually quite controversial. Some people think that the preclinical phase, or the phase before we can pick it up, lasts between 1 and 4 years, and we're learning more about this, and of course, the subtle warning signs and symptoms. It's a cancer that whispers to us.

The technique for screening for ovarian cancer has not changed over the past 20 years. It remains the ultrasound and the CA-125. The ultrasound is a pelvic ultrasound, or a transvaginal ultrasound, which is done with a radiologist or in an expert pelvic imaging office. CA-125 is a tumor marker which is a protein which is present on the tumor cells. This is what we can pick up in the blood of women who have ovarian cancer. The problem with a CA-125 is it lacks the sensitivity and specificity to really, adequately detect the disease.

The most recent data that came out with general population screening for ovarian cancer, which is the PLCO trial, which was a national trial, the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial, was published approximately a year, year and a half ago, and the conclusion was that there's no demonstrable benefit of ovarian cancer screening with a CA-125 and an ultrasound in the general population. However, this does not necessarily apply to women who are at elevated risk to develop the disease.

The newer data which has been published concerning the utility of CA-125 and ultrasound imaging actually doesn't use CA-125 as positive or negative. So it's not saying that my CA-125 is less than 30 so it's good, or less than 35 so it's normal. It's actually looking at the rate of rise of CA-125 over time. So this is quite important that the CA-125 be done at the same place, the same laboratory, and looking at that rate of rise of CA-

125 over time, combined with the ultrasound, may actually be better than when we compare it to just an absolute cutoff of CA-125 combined with ultrasound imaging. This data was recently published in the United States and it was published quite some time ago by Ian Jacobs and his colleagues in the United Kingdom in their National Health Service Screening Trials.

So stay tuned for more. This is called the ROCA algorithm, or Risk of Ovarian Cancer Algorithm. This is what people are beginning to look at and to screen for ovarian cancer, and looking at that CA-125 in a little more subtle fashion.

So what are the solutions? If our imaging and our tumor markers right now are not where we can apply them to the general population, however, we could have a conversation about them in high-risk populations. What are the solutions? Individuals are looking for additional tumor markers. We also need to realize that we probably need experts in pelvic imaging. We need to have people who know what the ovaries look like and what a normal ovary looks like. We're not looking for large things. Once we're able to find something large in the ovary, it's pretty likely that the tumor has had a chance to spread for most ovarian cancers. So we need to probably look for subtle changes in the ovaries, subtle changes at the distal end of the Fallopian tube, because now we also think that probably at least a third of ovarian cancer is coming from the distal end of the Fallopian tube. We really need to have people who are participating in pelvic imaging who have a great expertise in this.

The current recommendations of the NCCN Guidelines, which are our national cooperative group guidelines, suggest starting screening for ovarian cancer for women who are at elevated risk for the disease. They do not recommend screening in the general population. But those women who are at significantly elevated risk or moderately elevated risk, the women who are at moderately elevated risk should always have a conversation with their physician, however, or healthcare practitioner, about the utility in screening for their personal situation. But they should start - women should be screened between the ages of 30 and 35, or 10 years earlier than the earliest age of first diagnosis in the family of ovarian cancer. We generally start screening between the ages of 25 and 30 for ovarian cancer in our highest of risk women. Important to realize that the screening should actually be every 6 months. It's not a yearly exam. It's an every 6 months exam, because again, we want to detect subtle changes, the changes in rate of rise of CA-125. Current recommended screening modalities continue to be transvaginal ultrasound with color Doppler, so looking at the color flow, the blood vessels to the ovaries and then the ovaries. That's what Doppler imaging is. CA-125, and always combined with a pelvic exam. We can actually detect subtle changes on a

pelvic exam sometimes that imaging can't pick up, so always important to have that pelvic exam while the imaging is being done.

What are the risk reduction strategies for women who are at elevated risk? Well, screening. However, where we are right now with ovarian cancer screening, we can't guarantee that we'll pick up something early. We may be seeing a shift of something and picking up something early based with the Risk of Ovarian Cancer Algorithm that we're beginning to employ. Of course, chemo prevention with the use of oral contraceptives, risk reducing surgery, including bilateral salpingo-oophorectomy, removal of the tubes and ovaries. Some people now are talking about, and we're beginning to explore, the utility of just removing the tubes, or bilateral salpingectomy for women who are at significantly elevated risk for risk reduction. Those evaluations are currently ongoing.

So what is the future? Well, the future for screening is, we need to learn how to employ our techniques a little bit better, perhaps new tumor markers, and perhaps refine our risk reduction strategies also, because right now when we remove the tubes and ovaries early for women, we're putting people into a surgically induced menopause, which carries its own set of risk and quality of life issues. So if we can also work on better risk reduction for ovarian cancer, either through different surgical techniques or chemo preventative techniques, that will also help us.

Shera Dubitsky: Great. Thank you very much, Dr. Poynor. You know, we don't often hear as much about screening guidelines for ovarian cancer in the media, so we certainly appreciate you clarifying that for us and informing us. I think one of my favorite parts of your presentation is when you said, "Stay tuned for more," which makes me feel that I'm glad that there is continued research on the horizon.

We will now hear from a Sharsheret caller who also happens to serve on Sharsheret's Board of Directors, who also happens to be celebrating a birthday today. We're grateful to have Lisa Farkovits share her story and insights with us this evening. Lisa, go ahead.

IV. Personal Story

Lisa Farkovits: Thank you. First of all, I learned a lot from the prior speakers, and so I really appreciate them taking their time to do this call. Thanks again to Sharsheret for allowing me to speak.

Growing up, I was blessed to have a loving family, but they were old school and they didn't talk about certain things. I was also blessed to

have a very loving grandmother, but I was not told until my mid-teens that she was my step-grandmother. It took me a few more years until I was in college to learn that my original grandmother had passed away from breast cancer. While sad, I filed that information away and didn't think about it in the context of my breast health until much later. At the age of 24, I had a manual breast exam where my general practitioner felt a series of lumps that concerned her, so I scheduled my first breast sonogram. I was told following the sonogram that I have dense breasts with migrating cysts that make it difficult for anyone to get correct results performing a manual exam. The one good thing about that, for me personally, was that I didn't have to do manual exams.

When I was 27, as a precautionary measure, my OB-GYN asked me to have another sonogram, as once again I felt very lumpy. I went into the exam, and after a few minutes, the sonographer gasped, said, "Excuse me," and left the room. During my previous sonogram, I received the exam and the radiologist came in and told me the results a few minutes later. The reaction of the sonographer at this exam frightened me, and it took her a while to return with the radiologist. During that time I was crying. I pulled out my cell and called my parents, thinking the end was near. After 30 minutes, the radiologist came in, redid the exam, and informed me that while everything was fine, I had many cysts and had unusually dense breast tissue, which is why the sonographer reacted the way she did. She thought I was riddled with breast cancer. While relieved with the diagnosis, I gave her a lecture on bedside manner, which I hope she relayed to her sonographer, and once again put the matter behind me.

I came to find out through other procedures I had over the years that I had a predilection to cyst formation in many places inside my body, though after each procedure I was blessed to find out that once removed, nothing was cancerous. It kept me alert, but I never thought of it in the context of my ancestral genetics. Shortly after turning 29, I had a procedure to remove uterine cysts and a blood clot. The weekend following the procedure, I was blessed to get engaged to my husband. This blessing had the added benefit of me getting to know Rochelle Shoretz, then a young breast cancer survivor, and the founder of what was at the time a small organization called Sharsheret. It turns out she was first cousins with my husband, who had been involved with the organization.

Over the next few years, I became more involved with Sharsheret. Through them I learned that Ashkenazi Jewish women have a 10 times greater likelihood of getting genetic breast cancer than the population as a whole. After reading early Sharsheret material, I was able to put my

genetic history in the context of my medical history, and realized that I should be vigilant.

I became pregnant with my first child at the age of 30, while my husband was working as the IT manager for Sharsheret. I had my second child at 32, and while pregnant with my third child at 35, I decided it was time for me to develop my breast plan of action. During this period, I had an additional sonogram, and following the birth of my third child I made an appointment with a genetic counselor at the Leslie Simon Breast Care and Cytodiagnosis Center at Englewood Hospital. At my appointment, after running through my family history, which was unfortunately shorter than some due to the impact of the Holocaust on my family and the predilection of my family members to have an abundance of boys, it was determined that I have a high enough risk, given my personal and genetic history, that I should receive genetic testing. I also made sure that they put out the recent Sharsheret pamphlets that they had just reordered. The last batch had been taken and hopefully used by their patients.

The most valuable part of the process was developing a plan for managing my breast health, regardless of the results. Keeping in mind my personal history of my breast health, it was drilled in my head that whatever the results indicate, it will only indicate whether I am likely to have a few genes that are highly indicative of breast cancer. It wouldn't provide any indication on environmental or non-identified genes that could be responsible for breast cancer. After consulting with the counselor and my doctor, we determined that my breast plan, if I were positive, would be to have a radical mastectomy and oophorectomy. Based on my evaluation of my personal circumstances, my decision was based on my personal determination to be there as a parent for my children, than to have these organs. Our plan for a negative result was to have 1 more breast sonogram and mammogram before I was 40, following which, I would have them annually.

A couple of years after having my second child, Rochelle asked me to become more formally involved with Sharsheret, where I was invited to join a Sharsheret board subcommittee. Three and a half years ago, I was honored to be asked to join the Sharsheret board. I gladly said yes, as what I had learned through Sharsheret and having seen the impact of the organization through early involvement and referrals I made, it was clear to me how important the organization was to all Jewish women. We have to be informed. We have to understand our risks regarding our shared history. We also need information, which Sharsheret provides through material and access to its experienced, dedicated, and talented staff, to allow us to make intelligent decisions about how we manage our breast health.

While most people think of Sharsheret as an organization that helps Jewish women facing breast cancer, I have had the opportunity to experience Sharsheret as an organization that helps educate Jewish women about what they need to know to manage their breast health. In the case of Sharsheret, the knowledge they provide truly empowered me.

When I turned 40 last summer, I had my first official breast sonogram and mammogram. Following the exam, after reviewing the results, and re-reviewing my history, my breast team determined that I should now be adding a breast MRI to the diagnostic tools used to monitor my breast health. Based on the presentation tonight, I'm assuming I have pretty decently dense breasts. I received my prescription for my second official breast cycle a few weeks ago, and I will be scheduling my next round of annual exams next week for later this month.

Today is my birthday, and when Shira and Elana from Sharsheret reached out for me to do this call, it was important enough to me that I celebrated my birthday last night to be on this call tonight. I couldn't celebrate tomorrow night because I'm going to be on another call with our Sharsheret board subcommittee. Sharsheret has become an integral part of my life, and I derive a tremendous amount of fulfillment through my involvement. While Sharsheret is going through a period of transition in light of the untimely passing of Rochelle, I am excited to be involved in fulfilling her dreams and vision for Sharsheret's future. I'm also delighted to be working with Sharsheret staff, to help guide them through the next phase of growth we developed through our recent strategic planning process. Sharsheret gave me so much knowledge, I am happy to be able to give back in any way possible.

Shera Dubitsky: Thank you, Lisa. Your story, I think, highlights the many concerns that we often hear from young women, including challenges to learning about family history, family planning, and personalizing best screening practices for each individual woman.

V. Question and Answer

Shera Dubitsky: We now have time for questions and answers. Please keep in mind that we are asking you to keep your questions broad in scope, as we would like everyone on tonight's call to benefit from the discussion. To ask a question, please dial *1, or enter your question and the questions will be addressed in the order that they are received. We've already, over the course of your discussion, received a couple of questions, and it seems to be that I'm seeing a theme in terms of women who have been diagnosed with breast cancer and have completed active treatment. We've received a couple of questions about follow-up screening. So I think in terms of for

those diagnosed with breast cancer, Dr. Weinstock, if you can talk about follow-up screening for women who have either had a mastectomy, a bilateral mastectomy, or have done certain reconstruction surgeries, if you can address that. And then Dr. Poynor, if you can maybe address if somebody had their ovaries removed, how they can do follow-up screening at that point.

Dr. Lisa Weinstock: Okay, certainly. Patients who have had mastectomy without reconstruction or with implants, as of now there is no protocol for follow-up screening. I think, as Dr. Poynor said, I think in the future what we're going to be seeing is new guidelines for that. I think that MRI may be performed on patients, certainly to look at their implants. For patients with mastectomy, I think a very important point is to know that, is to continue to go to your breast surgeon, if that's what your breast surgeon asks you to do. It is important to have a good physical exam, and also to be aware of any changes, this is patients with mastectomy, any changes in their skin, any rashes. All that stuff is important, because recurrence can occur years and years and years after the mastectomy. So don't ignore the mastectomy side. There are no set recommendations in terms of imaging. Certainly patients who have had lumpectomies for breast cancer, I consider those very high risk women, and they get screened a minimum of annually, with most likely supplemental MRIs. That's my protocol.

Shera Dubitsky: Dr. Poynor?

Dr. Elizabeth Poynor: For women who have had their ovaries removed for either a BRCA1 or BRCA2 mutation, these women also are at elevated risk for primary peritoneal cancers, which are a cancer that look like ovarian cancer, act like ovarian cancer, but don't arise from the ovaries, so arising from somewhere in the peritoneal cavity or that lining of the peritoneum. So a woman with the BRCA1 or BRCA2 mutation who hasn't had an oophorectomy, or a salpingo-oophorectomy, the risk of developing a primary peritoneal cancer may be anywhere between 4% and 6%. Once the ovaries are out, that may actually drop down to about 1%. However, we still do consider women who have had their ovaries out and tubes out at risk for developing primary peritoneal cancer, and certainly, unfortunately, I continue to see this in my practice. For these women, again, there's no standard guidelines once you've had prophylactic surgery. However, most individuals will opt to do a CA-125 in their physical exams every 6 months, and of course, you listen for any subtle warning signs and symptoms of primary peritoneal cancer, which is similar to ovarian cancer. However, some women and some practitioners will opt also to do an ultrasound every 6 months.

Important also for women who have a BRCA1 mutation, we're realizing that maybe these women are also at elevated risk to develop primarily

papillary serous cancers of the uterus. So again, stay tuned for more information concerning this. These women may also opt to have some form of screening for the uterine lining. Again, no guidelines, no clinical trials, but just discuss with your healthcare practitioner.

Shera Dubitsky: Okay, and there's a follow-up question, Dr. Poynor. At what point should someone consider getting their ovaries removed, versus continued CA-125 screening?

Dr. Elizabeth Poynor: Well, we generally recommend for the women who are at highest risk with the BRCA1 or BRCA2 mutation, by the age of 35, or when childbearing is complete. So for women who are identified as having the mutation early in life, we have new reproductive technologies where we can freeze eggs so that women have some insurance that if they need to have their ovaries out that they still do have some fertility with frozen eggs. We generally recommend removing the ovaries by the age of 35, or when childbearing is complete. Some individuals we'll recommend a little bit of a shift for a BRCA2 mutation, because these cancers tend to occur a little bit later in life in the 50s. So women with a BRCA1 mutation, their cancers tend to occur, they tend to increase at the age of 40. That's when we start to see ovarian cancers in women with BRCA1 mutations.

So we start to recommend rethink your ovaries, consider it by the age of 35, or when childbearing is complete, maybe a little later in BRCA2 mutation carriers. However, I think every GYN oncologist I have known has had a patient, unfortunately, who's a BRCA2 mutation carrier who maybe waited a little too long to take her ovaries out. I generally make the same recommendation for women who carry both the BRCA1 and BRCA2 mutation. Then again, stay tuned for more information, as we get more information on these mutations and these lesser penetrant genes. Some of these are going to account for some ovarian cancers, and we're already seeing this. We don't really understand the ages of occurrence of ovarian cancers with these lesser penetrant genes, and this is the information that we're currently accumulating and getting that information right now as we do this and expand the genetic testing.

Shera Dubitsky: Okay, great. Dr. Weinstock, is it all Jewish women who are at risk, or just those who are of Ashkenazi Jewish descent who are at higher risk? Specifically, I guess, we're asking about women of Sephardic descent.

Dr. Lisa Weinstock: I believe it's just Ashkenazi. The link is to the Ashkenazi gene. It's nothing to do with Sephardic. I suspect that there are genetic links, not just Ashkenazi. We see Irish women who have family history is very similar to the Ashkenazi women. So in terms of Jewish, I believe it's just Ashkenazi. I don't see enough Sephardic women, to be honest with you.

Shera Dubitsky: Dr. Poynor, do you have any information on that?

Dr. Elizabeth Poynor: The Ashkenazi Jewish population is the founder mutation. Many ethnic groups, Finnish groups. There's some Latin American groups. The Irish groups that have found their mutations. But there is no group that has found their mutations at as high frequency as that 2% that's found in the Ashkenazi Jewish population.

Shera Dubitsky: I'm actually not sure which doctor to put this to, so I'll put it to both. If a person has been diagnosed with the BRCA gene mutation, and has had ovarian cancer, what is that person's risk of breast cancer?

Dr. Lisa Weinstock: I can't give you a number, but extremely high.

Shera Dubitsky: Okay. I don't know if it's so much a screening question, but we did get a question about what are the benefits versus the risks of taking medication to prevent breast cancer? Dr. Weinstock?

Dr. Lisa Weinstock: Yeah, that's very complex, and that's really for an oncologist to be discussing.

Shera Dubitsky: Got it. Okay. We've actually received a question in various different forms, about insurance. Do either of you experience any problems with insurance coverage for recommended screenings?

Dr. Elizabeth Poynor: I can answer for the ovarian cancer screening. The commercial carriers, we generally don't see a problem with. Medicare doesn't cover ovarian cancer screenings. There are no what we call Z codes, which are family history codes, for ovarian cancer screening in Medicare, and a diagnosis of breast cancer does not warrant ovarian cancer screening in our Medicare plans currently. So commercial carriers, we don't tend to see problems, actually. However, in Medicare, in the absence of any underlying pathology, with the appropriate family history code, or personal history code, it is generally not covered.

Shera Dubitsky: Okay. Dr. Weinstock, are you seeing anything?

Dr. Lisa Weinstock: With the breast screening, I think the coverage actually, if it's even possible, is getting a little bit better. Screening ultrasound is now a covered exam in New Jersey. I'm not sure about New York, but possibly, mainly because of this legislation. A lot of MRIs are now being covered due to risk assessment analysis. A lot of facilities are taking individual risk assessments and really going through the family history, and if you've got over a certain percentage, I think it's 20%, MRIs tend to be covered. So I

think the insurances are maybe covering screening in high risk a bit more than I've seen in the past.

Dr. Elizabeth Poynor: I think the difference between breast screening and coverage and ovarian cancer screening is lack of really hard data for ovarian cancer screening as it stands now. We're just now getting those subtle implications that maybe we're doing something with this Risk of Ovarian Cancer Algorithm right. So I think your screening for breast cancer is much more refined, and much better than it is for ovarian cancer, what are covered.

Dr. Lisa Weinstock: Breast cancer's also become so political, so it's been out there. I think the insurance companies may have been forced to start recognizing that. Hopefully they will for the ovarian screening as well.

Shera Dubitsky: Right. Okay, Lisa Farkovits, a question came in actually about communicating with family members. Is this something that you've had in your own family about discussing hereditary risk, and if so, do you have any thoughts or any advice about that?

Lisa Farkovits: My children right now are very young, and in terms of communicating to them, we haven't developed a strategy.

Shera Dubitsky: I guess maybe among cousins and aunts.

Lisa Farkovits: We've actually been trying to reverse the family history of keeping breast cancer quiet. I have one female cousin on my father's side, after many, many, many children. I had discussions with her. I have an aunt who also had uterine cancer, and so we had long conversations about family history and how I think she wished that she would have known at a younger age. She's also an endometriosis sufferer. We've definitely had these conversations. I've encouraged, given our family history of breast cancer. I've spoken to both of my brothers, who both have girls, that when the time is right that's something that they should have discussions with them as well, and something I'm happy to do for them if it's something that they're not comfortable with. They're more stringently religious than I am, and want to make sure that even despite that they have the level of awareness that they should probably have.

Shera Dubitsky: I also want to add that at Sharsheret we offer a family conference call. For the reason that Lisa just mentioned, either whether it's too taboo to talk about, or if people are really all across the country, we can facilitate a family conference call where you get family members on the call with a staff member, and we can all have the discussion around your particular family's genetic risk, all in real time and at the same time.

We have one final question here, and I guess it will go to Dr. Poynor. Are there any studies that speak to estrogen reducing medication increasing the risk of ovarian cancer?

Dr. Elizabeth Poynor: I don't think we have ... No. You know, Tamoxifen was actually. Tamoxifen had a similar ring. So the risk reduction strategies for breast cancer, Tamoxifen and aromatase inhibitors, so Tamoxifen has the same ring structure as Clomid, which actually is a fertility drug, that when used over a 10- to 12-month period of time will increase your risk of developing ovarian cancer. We haven't seen that with Tamoxifen. Tamoxifen is notorious for causing cysts, but they're benign cysts from stimulation of the ovaries, basically. Then with the aromatase inhibitors, we tend to see like little cysts develop, but no increased risk of developing ovarian cancer.

VI. Conclusion

Shera Dubitsky: I want to thank you for your questions. Everything Sharsheret does is driven by conversations and feedback that we hear from you. You will be receiving an online evaluation, so please take a few moments to complete this. Your feedback is truly invaluable to us. I would like to thank BioMarin, again, for their generous support in making tonight's program possible. I would also like to thank our speakers for sharing their expertise, their insights, and their time. You will be able to access the transcript and audio of our webinar on our Sharsheret website. If you go to Resources, you'll see that in the transcript. Finally, I'd like to thank all of you for joining us this evening. If you would like to continue this discussion with a member of our support staff, please feel free to connect with us by either calling the office, emailing us, or just going online. I also want to invite you to follow us on Facebook and Twitter. Just remember that we are here when you need us and as you need us. I want to wish everybody a good night, and again to thank you to our panel of speakers for a very informative evening. Take care.

VII. Speakers' Biographies

Dr. Lisa Weinstock is the director of Women's Digital Imaging of Ridgewood, NJ. Dr. Weinstock founded Women's Digital Imaging (WDI) in 2004 to provide breast, pelvic and bone imaging studies for women in a comfortable environment with immediate results, to minimize anxiety. Dr. Weinstock has specialized in breast imaging for over 18 years. Dr. Weinstock completed a fellowship in Breast Imaging at Columbia Presbyterian University Medical Center and a four-year residency in Diagnostic Radiology at Hackensack University Medical Center. She was an intern in Anatomic Pathology at Montefiore Medical Center and attained her M.D. from the SUNY-Health Sciences Center of Brooklyn.

Elizabeth Poynor is a gynecologic oncologist and advanced pelvic surgeon. Dr. Poynor's practice focuses on the care of women who are at elevated risk of developing cancer based on an abnormal Pap smear, her personal medical history, or family history of cancer. She has special expertise in the complex management of women and their families who have a genetic predisposition to developing breast cancer and gynecologic malignancies. Dr. Poynor also provides gynecologic care for women who currently have or have survived cancer, and may be experiencing side effects from prior or ongoing treatments. Dr. Poynor has co-authored numerous publications and book chapters on topics in gynecology and gynecologic oncology, and has lectured nationally, internationally, and through the national media. She has also appeared as an expert commentator on MSNBC, the Today Show, and WCBS. Dr. Poynor serves on Sharsheret's Medical Advisory Board.

VIII: About Sharsheret

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

Since Sharsheret’s founding in 2001, we have responded to more than 47,000 breast cancer inquiries, involved more than 4,300 peer supporters, and presented over 250 educational programs nationwide. Sharsheret supports young Jewish women and families facing breast cancer at every stage--before, during, and after diagnosis. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life. All Sharsheret’s programs are open to all women and men.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer
- Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors
- Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare professionals

IX: Disclaimer

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

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