

New Breast Cancer Screening Guidelines: What Do They Mean for Me?

**National Teleconference Transcript
Tuesday, November 24, 2009**

Presented By



Linking Young Jewish Women in Their Fight Against Breast Cancer

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I. Introduction
Rochelle Shoretz, Founder and Executive Director

Rochelle Shoretz: Thank you all for joining us this evening as Sharsheret presents the teleconference, *New Breast Cancer Screening Guidelines: What Do They Mean for Me?* I am Rochelle Shoretz, the Founder and Executive Director of Sharsheret and I'm delighted to welcome you all to the call tonight.

The media has been abuzz with news of the revised breast cancer screening guidelines released by the United States Preventive Services Task Force last week. A complete copy of the Task Force's recommendation statement can be found online on our blog at www.sharsheret.blogspot.com for those who would like to read those recommendations in their entirety.

Tonight we will hear from two health care professionals who will address the questions you may have about appropriate breast cancer screening for women at ordinary risk and those at high risk of developing breast cancer.

Specifically, we will discuss the implications of three of the revised guidelines. First, the Task Force now recommends against routine screening mammography in women ages 40 to 49 years. Second, the Task Force recommends bi-annual screening mammography - meaning mammography every two years - for women ages 50 to 74 years. Third, the Task Force now recommends against teaching breast self-examination.

It's important to note that the revised guidelines are merely those. They are guidelines and they are not binding. The American Cancer Society, Susan G. Komen for the Cure, and a number of other cancer organizations have taken the position that they will not modify their screening recommendations in response to the new guidelines and still encourage screening that begins at age 40 for those who are not at high risk of breast cancer, for whom earlier screening may be appropriate.

At Sharsheret, we are encouraging every woman to consult with her health care provider about the method and frequency of screening that is appropriate for her, given her medical and family genetic history.

Why are so many women and health care professionals up in arms about the revised guidelines? Well, for many of us who were diagnosed as I was before the age of 40, the notion of being asked to wait until we are 50 to be screened by mammography for the first time seems preposterous. As one Sharsheret caller wrote to us last week, "I am a strong advocate of mammograms before age 50, having been diagnosed at age 35. Yes, there are false positives and young women with dense breasts for which mammography may not be as effective, but isn't saving even one life worth it?"

Many of us discovered our own lumps as a result of self-examination. In fact, in almost half of the women in Sharsheret's database, cancer was detected before the age of 50 either as a result of mammography or self-examination. On the other hand, we acknowledge the questions we field from women and health care professionals with genuine concerns about exposure to unnecessary radiation or biopsies.

Tonight's experts will walk us through the questions you may have about how to be screened and how often, whether you are at ordinary risk of developing breast cancer or at higher risk. It is with pleasure that I now introduce Dr. Thomas Kolb, a radiologist in private practice in New York, who has been a member of Sharsheret's Medical Advisory Board for eight years. Dr. Kolb specializes in the detection and diagnosis of breast cancer predominantly in pre-menopausal women. He is also an Assistant Professor of Radiology at the Columbia University College of Physicians and Surgeons. Dr. Kolb's complete biography will be available online at www.sharsheret.org. Tonight, he will discuss screening for women at ordinary risk and we are grateful to have him with us.

II. Screening for Women at Average Risk of Developing Breast Cancer Dr. Thomas Kolb

Dr. Thomas Kolb: Thank you, Rochelle. It's a daunting task and a very short amount of time to discuss the new screening recommendations and how they came about. I'm going to focus on the science for now and in the question and answer period, maybe we'll be able to take some questions as to how these recommendations will play out in the future.

In the past two weeks it's definitely been a blizzard of information that has certainly descended upon the American public that has questioned the validity of the current recommendations for screening mammograms. I'm going to focus on two publications. One is the United States Preventive Service Task Force publication. The second is a publication in the journal of JAMA by Dr. Esserman. Both are very important because they questioned the validity of our current recommendations.

In the publication from JAMA, which was published about two weeks ago, they point out that the screening mammogram is an imperfect tool capable of finding progressive cancers early and presumably of saving lives, but also guilty of over treating non-lethal cancers. We'll talk more about over treating in just a little while. They also pointed out that screening mammograms are not performed often enough to detect lethal tumors and that's the failing of the screening mammogram.

Next, the U.S. Preventive Service Task Force - and we'll just call them the Task Force for now - published recommendations as Rochelle mentioned. But I do want to note at the very outset that even though their recommendation is against routine screening mammography in women ages 40 to 49, they do go on in the next sentence and say,

“The decision to start regular, bi-annual screening mammography before the age of 50 should be an individual one and take patient context into account, including the patient’s values regarding specific benefits and harms.” There is subjectivity built into the recommendation as well.

Let me start from the beginning. A mammogram is the only screening test proven to save lives in patients who develop breast cancer. Physical examination performed by a clinician, performed by the patient herself at regular intervals, ultrasound examination of the breasts or screening breast ultrasound, and MRIs, have never been proven to save lives. The studies, in terms of ultrasound and MRI, have never been done whereas physical examination has never been shown, when studied, to save lives.

There have been randomized clinical trials for mammograms, for screening mammography, performed over the course of the past 30 years, which consistently showed an overall reduction in death rate of 15 percent in younger women ages 40 to 49, and 28 to 30 percent in older women 50 to 69 years of age.

Every couple of years there are people who disagree that there’s any benefit to screening mammograms in women who are younger. They should consult the current Task Force Report itself, which reviews all previous studies and updates all relevant new studies from 2001 to 2008. It concludes that trials of mammography screening for women ages 39 to 49, indicate a statistically significant 15 percent reduction in breast cancer mortality for women randomly assigned to screening versus those assigned to controls.

The Task Force report itself agrees that based on clinical trials - which is the best data we have that is patient-based or clinically-based - 15 percent of the women who would develop breast cancer, would have their lives saved if they were to be screened. That's very important to understand.

Now if you look at the results of these trials, in the Task Force publications and *Annals of Internal Medicine*, you'll note that the numbers needed to be screened to prevent one breast cancer death in younger women, 39 to 49 years of age, is 1 out of 1,904 women. In the older age group, 50 to 59, it's 1 out of 1,339 women. We have to screen more younger women in order to save an equivalent amount of lives.

There are definitely problems in the trials that have been pointed out by many over the years, so the Task Force took it upon themselves to look at it a different way. They used medical models to estimate the benefits of screening women, the resources involved to screen these women, and the harms of various stopping and starting points and various intervals at which patients should be screened.

That means they didn't perform any additional patient studies, they didn't perform any other trials, they used a mathematical model which included all of these variables to determine which would be the best way or the most efficient approach to screen women to find the most breast cancer while conserving resources. They looked at gains in life years and death averted while consuming fewer resources. While they don't talk about costs of mammograms in their publications, they certainly are factoring in the costs.

They do say that for a particular model, a strategy that requires more mammograms but has a lower relative percent of mortality reduction is considered inefficient. The key word here is efficiency. They will concede that there will be women who will die if younger women are not screened and that some of those women will die that would not have died if they were screened. They will concede that. Their findings are, by using these mathematical models, that by adding screening to younger populations in women ages 40 to 49, they could have an additional mortality reduction of 3 percent. Remember, the trials showed a mortality reduction of 15 percent.

Now, these mathematical models are not foolproof. They are to be evaluated with caution; there's no question about that. They found a smaller mortality reduction than the clinical trials and there's probably some ground between the mathematical model and the clinical trials. But there's no question that there is a concession that a certain percent of women, a significant percent of women at normal risk, will die of breast cancer if they are not screened from the ages of 40 to 49.

Their findings were that by screening bi-annually, once every two years between the ages of 50 and 69, mortality reduction would be 16.5 percent which is much lower than the 28 to 30 percent that the trials showed. The data from the ages 50 to 69 in the trials is much stronger than in the younger age group, 40 to 49. We've seen a consistent decrease in the estimated mortality reduction or estimated number of lives saved by using these mathematical models, as opposed to looking at trial data of actual patients being screened with mammograms.

They also found that by screening every other year, they maintained "a benefit of 81 percent than if screened annually." Here they are

conceding that 19 percent of the benefit, which they believe is important between the ages of 50 and 69, will be lost by going to once-every-two-year screening rather than annual screening. They are conceding deaths in both the 40 to 49 year-old range and the 50 to 69 year-old range.

Essentially the question is where to draw the line, who should draw the line, and what resources we should use for screening women for breast cancer. I'm not attacking any of the science. I'm really questioning how it is being applied to their recommendations and how it will play out in the future. As you know, Secretary Sebelius of Health and Human Services said there will be no change in government recommendations as they stand now or government guidelines as they stand now for screening mammography.

Next, we move on to the second publication by Dr. Esserman in JAMA. That paper looked at how good mammograms are by using biologic criteria. Instead of using mathematical models of how efficient we are at screening for breast cancer, they looked at the biology of breast cancer tumors. Basically, they argue that mammograms are imperfect. They're capable of finding progressive cancers early and saving lives, but they're also guilty of overtreatment.

Let's stop for one second and talk about overtreatment. There's no question that we do find cancers by using screening mammograms that may not progress on to being invasive. There are non-invasive cancers and some percent of them will not progress on to be life-threatening to women. The problem is we don't know in advance which cancers will go on to be invasive and which won't. When we talk about overtreatment, it's really theoretical - it's not a practical argument, it's more theoretical than anything else. If we knew in

advance which patients would not have their tumors go on to be invasive, we could avoid over-diagnosing or over-treating those patients.

In essence, they argue in this JAMA publication that there are certain cancers that are lethal. Mammograms are not done frequently enough to detect breast cancer, so these cancers go on to become invasive and metastatic and kill patients before we can find them or even after we do find them. They argue that mammograms are imperfect.

Now of course, while thoughtfully written, this is nothing new. We do know that mammograms do better in older women, ages 50 to 59 and above, than they do in younger women. One obvious difference between these two age groups is breast density. That is, two-thirds of women pre-menopausal have dense breasts; 25 percent of women post-menopausal have dense breasts. Breasts don't change from dense to non-dense overnight - it's a progression of years. In general, statistically speaking, premenopausal women, or those 50 years of age and younger, are dense and the majority of women post-menopausal who are in the older age group are not dense.

This raises two possibilities as to why mammograms are less sensitive in women who are younger. One is that their tumors are aggressive. No matter what you do it doesn't make a difference, these patients will die. The second possibility is that we're not finding tumors because these women have dense breasts. We do know at this point, and this is work we've published a long time ago now, that mammograms decrease in sensitivity as breast density increases.

We have two choices - we can either throw our hands up and say, let's not do anything for this younger age group, our current screening

methods or routines are inefficient, as the Task Force would say. The paper in JAMA would claim that mammograms are not effective enough in younger women, so let's abandon screening in younger women.

Another approach would be - how else can we find these tumors? That brings us into a whole other realm which we can go to in the question and answer period. It goes into a whole other realm of ancillary testing. In other words, not just stopping with a screening mammogram, but looking further to try to find tumors while they are at their earliest and most treatable.

The bottom line here, to recap, is that there is good science in the Task Force papers. But science ends at the creation of these mathematical models, and supplying the variables into these mathematical models, and then becomes subjective. How can we subjectively analyze the results of these mathematical models and how should we "ration care" or limit mammograms to various groups of women? I would say that the government has a moral obligation to save lives and there are significant lives that can be saved based on either the trial data or even in the mathematical models that are published by the Task Force, and certainly in annual versus bi-annual screening.

These reports have certainly left us with questions and I think we have to be very, very careful on how the science is interpreted and applied to large populations of women today.

Rochelle Shoretz: Thank you, Dr. Kolb. That was a very helpful synthesis of these two very important publications. I know during question and answer we'll sort of push you on the question of what should women of ordinary risk be doing in your opinion?

I'd like to now introduce Niecee Schonberger, Sharsheret's Genetics Program Coordinator. Ms. Schonberger has provided genetic counseling in all aspects of the field and has focused on cancer genetics for the past 10 years. A founding member of the National Society of Genetic Counselors, Ms. Schonberger's biography will be available online at www.sharsheret.org. Tonight she will discuss screening for women at high risk of breast cancer, and I want to thank her for being with us tonight.

III. Screening for Women at High Risk of Developing Breast Cancer Niecee Singer Schonberger, MS, CGC

Niecee Schonberger: Thank you, Rochelle. Good evening, everybody. I certainly understand the angst that's been generated by this report. The most important thing to remember is that the report specifically states these are guidelines for women at average risk, not for women with increased risk.

For those of you who are at high risk of developing breast cancer, for instance carriers of a mutation for breast cancer or who have strong family histories of especially early onset cancer, these guidelines do not apply to you. The guidelines for high risk women are the same as ever, and I'll review them with you tonight.

These recommendations for high risk women were developed by a Task Force of the Cancer Genetic Studies Consortium and are applicable to BRCA mutation carriers and to women who have a substantial likelihood of being mutation carriers where the family history is significant for early onset breast cancer, but no mutation has yet to be identified. Mutation carriers have up to an 85 percent chance to develop breast cancer in their lifetime and in excess of a 50 percent chance to develop a second breast cancer after a first one.

Here are the recommendations. Again, these are for high risk women. First is the importance of self-examinations preferably on a monthly basis. It's vital to early detection to distinguish between what is normal in the breast and what isn't. The recommendation is that self-examinations should begin by age 18 to 21 years of age to establish a regular habit and allow familiarity with the normal characteristics of breast tissue. This should be done in the shower and you can best

remember to do it if you pick a consistent date of each month, for instance, your birthday date or the first day of each month.

Secondly in the recommendations, is the yearly mammogram starting between ages 25 to 35. Remember again, we're talking only about high risk women. Mammography is typically only done once a year because of the radiation exposure. Even though mammograms use very low dose radiation, you don't want to have any more exposure than is necessary. In between the mammograms at the six-month interval, it's recommended to have an ultrasound which is non-invasive and doesn't use radiation.

Lastly, clinical examinations beginning at ages 25-35 by your physicians are very important. The recommendation is to see a physician, either your general practitioner, your Ob/Gyn, your oncologist, every three to four months. This way if anything pops up that's unusual, it can be dealt with early with the greatest prospect for a good outcome.

These recommendations for high risk women are not set in stone but are guidelines that need to be discussed with your health care provider, so that an individualized screening plan can be put in place based on a woman's family and medical history.

At the center of the matter is having a thorough knowledge of one's family history to determine which guidelines are appropriate for you. Probe your history with the help of the family historian. There's usually one in every family, someone who knows everything about everybody. This is important to learn who had what type of cancer in your family and at what age they were diagnosed. Early onset cancers are more

suspicious of a genetic predisposition since cancer is generally a disease of older age.

This then can be followed by a meeting with a genetic counselor to review what you've learned and receive cancer risk assessment that's appropriate to you. This process can help to put your risk in perspective and guide you through the current maze of recommendations.

I spoke with a woman recently, we'll call her Sarah, who was 37 years old and asking about genetic testing. She was unaffected by cancer, but had heard a lot about the BRCA mutation analysis and the relationship with Ashkenazi Jewish women and she wondered if this was something she should have. When I asked her about her family history, she said her parents were both deceased, never had cancer, and she didn't know of any cancers in the family. I suggested that she speak with her relatives just to be sure, but if there was no cancer in the family, genetic testing was not something she had to consider.

When she called me back a few days later, she appeared stunned. It turned out that her father's sister's daughter, her first cousin, had breast cancer when she was in her forties, had genetic testing, and was positive for the mutation but hadn't thought it was important to share this with Sarah since it was on her father's side of the family.

These mutations can be passed on through either the father or the mother, so now mutation testing was indicated for Sarah. It turned out the best of all results, because she turned out to be negative for the family mutation and her risk was now the same as that in the general population. The moral of this story is ask questions. Your family

history can change your level of risk, either up or down, and determine just how you should be screened.

The debate about the new guidelines will most likely go on for some time and various studies will be put forth to justify or negate the findings. A Massachusetts retrospective study of some 7,000 women reported on this year at the ASCO Breast Cancer Symposium found that 20 percent of women who did not undergo regular screening mammograms accounted for almost 75 percent of breast cancer deaths. This result certainly muddies the waters and leaves the average woman with immense conflict.

The take-away message for every woman is a discussion with her doctor. The take-away message for high-risk women is to discuss the established guidelines for mutation carriers, as outlined here, with her doctor also in order to be either reassured or to best protect yourself by identifying your cancer when it's small and treatable.

I am the coordinator of the Genetics for Life Program at Sharsheret. I'm available at all times to take your calls and answer your individual questions and concerns, not only about these guidelines, but also about your family history, genetic testing, and cancer risk assessment. We also have booklets, information packets, and other resources on the subject of genetics that we can share with you.

If you've already had breast cancer, learning more about your genetic background may provide risk assessment for yourself as well as for your family members and may influence your health care decisions and screening modalities.

If you haven't been diagnosed with breast cancer but have a strong family history, learning more about your genetic background may help you identify options that could reduce your risk of developing cancer or assist in detecting cancer early.

Rochelle Shoretz: Thank you so much, Ms. Schonberger, for walking us through the modalities of screening that are important for those at high risk. Again, I just want to highlight that Sharsheret's Genetics for Life Program is really a wonderful resource for women and families with questions about the risk of hereditary breast or ovarian cancer. We encourage you to reach out to us with your questions or for more information.

IV. Question and Answer Session **Moderated by Rochelle Shoretz, Founder and Executive Director**

Rochelle Shoretz: I'd like to open the floor for your questions. We will start with Dr. Kolb. Ms. Schonberger mentioned that the take-away message in all of this is that there needs to be a discussion with your doctor, and that's certainly something we're advocating here at the organization. You are that doctor for so many women. Can you tell us a little bit about what women are asking and how you are guiding them in terms of the average risk woman screening modalities?

Dr. Thomas Kolb: For average risk or normal risk, I'm guiding them as I spoke earlier. I believe that we have moved away from patient care to an efficiency model, and it's pretty cold and calculated. We have to be very careful, because as I said, there's a concession by the Task Force itself that women will die based on their recommendations for new guidelines. I believe that until we have much more information, it behooves us to continue down the path that we're going now to screen normal risk women once a year with a mammogram beginning at the age of 40.

Rochelle Shoretz: Are there any other screening modalities that are being tested to replace the mammogram? Almost every October there is some controversy kicked up in the media about mammograms, but is there anything that's being studied to replace it?

Dr. Thomas Kolb: First of all, let me just say the controversy every year, every two years, centers around the trials. You see here even the Task Force acknowledges that the trial results are valid, that there's a significant reduction in death rate by doing annual mammograms from the age of 40 on.

In terms of newer modalities, a screening breast ultrasound is a very good tool. It finds an enormous amount of breast cancer in women with dense breasts that otherwise would not be seen on a mammogram. It finds 40 percent additional breast cancer that would be missed on a mammogram in women with dense breasts. The benefit of screening breast ultrasound is obvious - it finds an enormous amount of additional cancer. The other benefits are that it's relatively cheap and takes a relatively short amount of time to perform. In the literature, you'll find large quantities of time necessary to perform one. But in standard practice and the way I do it, it takes about five minutes to perform a complete screening breast ultrasound of both breasts.

The next test we have is MRI which is used more routinely on women that are very high risk, generally with two primary family members with a history of breast cancer. MRI will find an additional 10 to 15 percent of breast cancer not seen on a mammogram or on ultrasound. In women with dense breasts, mammograms may only find about 40 to 45 percent of breast cancer. Ultrasound will add an additional 40 percent and MRIs will find an additional 10 to 15 percent above that. When you look at the literature and they talk about MRI finding 60 to 70 percent additional breast cancer, they're talking about over the mammogram alone, not with the mammogram and ultrasound.

This issue has not been studied enough. There is an ACOR trial, which is the American College of Radiology trial, for screening ultrasound and they've published their results within the past year, confirming what I just told you about screening breast ultrasound. They are adding one year to the study and comparing screening ultrasound with screening MRI, which will be a very important finding, a very important study, to be reported within the next two years.

The positives of breast MRI are just that - finding more cancers. The negatives are that it's relatively expensive. You're in the MRI magnet for 30 to 40 minutes and it requires intravenous contrast for each examination. The false positive rate, while there's a false positive rate for every test, mammograms, ultrasound, physical examination, and MRIs as well and that has to be tolerated.

In terms of replacing the mammogram, there is a test called digital breast tomosynthesis which is about one or two years away from being evaluated by the FDA to see whether it has a benefit or not. It is a type of a mammogram, but instead of getting two pictures of breasts for each compression, we would get approximately 50 to 60 pictures of the breast, almost like a CAT scan of the breast. It may give us more information, but we'll have to wait a little while to know that.

There is breast-specific gamma imaging, which is a nuclear medicine test you may have heard of, where you get an injection of technetium which is a radioactive compound. Very small studies - and many more studies have to be done or larger multi-center studies would have to be done - confirm the initial early, very early results of very high sensitivity and higher specificity, which means less false positives than MRI. However, there is a radiation dose involved that is even higher than a mammogram and I don't see it being used routinely for screening for breast cancer.

That's basically where we are. Now there are fringe tests as well, but those are the mainstream tests that are available now.

Rochelle Shoretz: Dr. Kolb, one follow-up question to that. In addition to mammography, ultrasound, MRI, and some of the newer tests you mentioned, where do self-examination and clinical examination come in to all of this? I

know that a lot of the women who are calling in are asking about breast self-examination. Is there really a downside to it? Perhaps we shouldn't be teaching it, but should we be discouraging women from doing it? That doesn't necessarily seem rational.

Dr. Thomas Kolb: No. The way I approach it is that women who are very comfortable and motivated to examine their breasts, should examine their breasts. However, there are large numbers of women who are anxious about examining their breasts, afraid of missing something, afraid of finding something. They live in fear of examining their breasts. Those women, whatever percent they comprise, should not be told that if they don't examine their breasts, they're doing the wrong thing. In other words, it's okay not to do breast self-examination because there really are no studies showing a decrease in the mortality rate by doing either clinical or self breast examination.

One study we did that was widely published and publicized was that ultrasound, a screening breast ultrasound, will find 80 percent of breast cancer and 90 percent of the time Stages 0 and 1. Clinical breast examination found 27 percent of breast cancer and when it's found, 40 percent were Stages 0 and 1, which are early stages. If you're going to choose what to do in terms of just science alone, in terms of going to your breast surgeon for just checkups or oncologist for checkups, a screening breast ultrasound is far more effective at finding early breast cancer than any kind of physical examination is. I do leave it to the patient to decide whether they want to perform their own physical examination or not.

Rochelle Shoretz: Thank you, Dr. Kolb. Ms. Schonberger, another caller asks, "How do I know if I'm a woman at high risk or a woman at ordinary risk for purposes of tonight's discussion?"

Niecee Schonberger: It really is a matter of the family history. You're at high risk if your family is indicative of a genetic predisposition. In other words, there are multiple family members with breast or ovarian cancer, particularly the breast cancer at early ages, and then there may be a genetic predisposition in the family.

Most breast cancers - 90 to 95 of breast cancers - are not inherited, so just having breast cancer doesn't mean that you're at high risk. If you fall into the other percentage of the 5 to 10 percent, then that's considered to be at high risk, whether or not a particular genetic predisposition can be identified. Although we know a lot about this genetic testing, we don't know everything yet. The women who are at high risk are the ones who have the family history of early-onset breast cancer and ovarian cancer.

Rochelle Shoretz: Thank you so much. Dr. Kolb, another question comes in from a caller who wants to know, "How much radiation is really associated with a mammogram? I've heard that it can be as little as the exposure one has when flying on an airplane, but I've also heard that I may be putting myself at risk for cancer with too many mammograms. Which is true?"

Dr. Thomas Kolb: Both are true. The estimated risk of flying cross-country is equivalent to a single mammogram. However, there's always a theoretical risk of developing breast cancer by having repeated mammograms or annual mammograms. This has all actually been calculated out. It's not the actual numbers of breast cancers that can be caused by radiation of any sort - whether it's CAT scans, whether it's the breast-specific gamma imaging that I was talking to you about before, or whether it's

for mammograms – it has been calculated out by the latest BEIR VII report.

If anyone is interested, it's a government agency that puts numbers out of theoretical risks. You don't want to overdo mammograms if there's not medical necessity. The only reason to do a test that subjects anyone to radiation would be when there is a medical benefit associated with that test. Patients who are high risk have come in wanting two mammograms a year and I dissuade them from having that done.

Rochelle Shoretz: Ms. Schonberger, a very specific question has come in from a caller, but I think it's one that I'm sure many women on the call tonight share. This is a woman who was diagnosed at a young age, younger than 50, and tested negative for the BRCA1, BRCA2 mutations. Do her daughters have higher risk? Do they end up falling into the average risk category or the higher risk category of women, with respect to the guidelines tonight?

Niecee Schonberger: That's a terrific question and it's a very difficult one to answer. First of all, there are two levels of genetic testing. They both involve the BRCA mutations. There are three tests associated with Ashkenazi Jewish ancestry. That's called a multi-site testing and usually that's the test that's done first. Then there's the comprehensive test on the same two genes that looks at well over one thousand mutations.

If the woman had the comprehensive test that looked at all thousand mutations and she was negative and there was no other family member with breast cancer, you can't say categorically that this is not a genetic situation. Because there are still limitations to the testing, although they know thousands of mutations, there are probably others

that can't be tested for or identified yet. There may be other genes that can't be identified yet.

Her daughters are probably at slightly increased risk because of the fact that she had breast cancer at that age, but they would not be candidates for any testing, because if the mother did not have a genetic mutation that can be identified, then there's no point in testing the children. However, until we get more specific testing that's more precise, the daughters should consider that they are at slightly increased risk over the general population.

Rochelle Shoretz: Thank you, Ms. Schonberger.

Dr. Kolb, what are the possible implications, if any, on insurance coverage for mammograms as a result of the guidelines? Is this something about which women should be concerned?

Dr. Thomas Kolb: That's the big question. Everyone should be concerned. If these recommendations are accepted as guidelines, they would ration screening mammograms to every other year for women only between the ages of 50 and 74. Other women would not be offered mammograms and would not be reimbursed for mammograms if it's not within those recommendations. Medicare would limit mammograms or could conceivably not pay for mammograms over the age of 74. And of course, private insurers apparently would be more than happy to not reimburse women for mammograms under the age of 50. There are significant ramifications.

Even though Health and Human Services has repeated that they are going to keep the current guidelines in place, they will certainly be

open for a debate due to these reports that have emerged in the last two weeks.

Rochelle Shoretz: Something definitely to keep one's eye on. Dr. Kolb, one final question. Our caller asks, "I've already had breast cancer, now what? What kind of screening should I have and what should I make of the new guidelines?"

Dr. Thomas Kolb: What I do is differentiate patients based on age and breast density. It really depends a little bit on how old the patient is.

In a younger woman with dense breasts who's had breast cancer, I'll do a mammogram and if she has dense breasts, a sonogram at the same time. It's a mammogram and an ultrasound at the same time. In six months, in between the mammograms, I will do an MRI - if she can tolerate having an MRI. Certainly if there's another primary family member with breast cancer, I'd be more inclined to do an MRI at six months. If the patient, for whatever reason, could not have an MRI, whether it's cost or claustrophobia or so on, I would then do another, a second, ultrasound in six months.

If the patient does not have a dense breast but has a fatty breast, the mammogram alone suffices. At the initial date of screening and at six months again, I would consider having that MRI for a second screen.

Rochelle Shoretz: And that's for women who've had lumpectomies?

Dr. Thomas Kolb: That's right, or mastectomies for that matter, either way, any history of breast cancer in a patient.

V. Teleconference Conclusion Closing Remarks

Rochelle Shoretz: If there are no further questions, I just want to remind everyone that Sharsheret is now encouraging every woman to consult with their health care provider about the method and frequency of screening that is appropriate for her, given her family and medical genetic history.

I want to thank Dr. Kolb and Ms. Schonberger for joining us tonight to discuss the revised breast cancer screening guidelines. A transcript and audio recording of this teleconference will be available on Sharsheret's website, www.sharsheret.org. We also encourage you to visit our blog at www.sharsheret.blogspot.com and let us know what you think of the new guidelines. You can read about our upcoming events, watch recent TV coverage of Sharsheret, and learn more about the programs and services we are bringing to women across the country.

Thank you all and have a good night.

VI. Speaker Bios

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.

Niecee Singer Schonberger, M.S., C.G.C., is Sharsheret's Genetics Program Coordinator. Ms. Schonberger graduated from Sarah Lawrence College with a Master of Science in Human Genetics. She has provided genetic counseling in all aspects of genetics and for the past 10 years, has focused on cancer genetics. She is a founding member of the National Society of Genetic Counselors and a past president of the Human Genetics Association of New Jersey. Ms. Schonberger provides supportive counseling, information, and resources regarding hereditary breast cancer to women diagnosed and at high risk of developing breast cancer.

VII. About Sharsheret

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

Sharsheret has developed the following programs in response to the needs of young Jewish women facing breast cancer.

The Link Program

- *Peer Support Network*, connecting women newly diagnosed or at high risk of developing breast cancer with others who share similar diagnoses and experiences;
- *Embrace*, supporting women living with advanced breast cancer;
- *Genetics for Life*, focusing on hereditary breast cancer;
- *Family Focus*, providing resources and answering questions of caregivers and family members.

Education and Outreach Programs

- *Health Care Symposia* on issues unique to younger women facing breast cancer;
- *Sharsheret Supports*, a national model for local support groups;
- *Sharsheret on Campus*, outreach to college students;
- *Facing Breast Cancer as a Jewish Woman* educational resource booklet series;
- *National Volunteer Program* sharing Sharsheret's mission through representatives and programs across the country.

Quality of Life Programs

- *Busy Box*, for young parents facing breast cancer;
- *Best Face Forward* to address the cosmetic side effects of treatment.

VIII. Disclaimer

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

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