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## For Long-Term Survivors: Understanding and Using Your Treatment Summary

February 23, 2008

Frances M. Palmieri, RN, MSN, OCN

### VALERIE KRAUS:

My name is Valerie Kraus, and I'm a volunteer with LBBBC, one of the sponsoring organizations here. I was diagnosed with breast cancer 12 years ago and attended the very first conference that was held in Philadelphia. Your speaker, Frances, was sharing something with me before that she will share with you about her recent athletic endeavors. One of the ways that I have handled my long-term survivorship is becoming more active physically, and I celebrated my tenth anniversary with a fundraising climb of Mount Kilimanjaro in Africa. In a blinding snowstorm. But this is an annual event, and if anybody is interested in it, it's a climb for breast cancer survivors and their supporters. I'll be available afterwards if anyone has any questions about it.

Your speaker today is Frances Palmieri, who is a clinical nurse specialist and nurse manager at the Multidisciplinary Breast Clinic and coordinator of the breast cancer program at the Mayo Clinic right here in Jacksonville. She oversees research activities, clinical management and education for staff and people with breast cancer. She developed and manages ongoing educational and research programs both at the Mayo Clinic and within the North Central Cancer Treatment Group, which is NCCTG. She developed and oversees the Mayo Clinic's NCCTG affiliate research program and serves as the liaison to the NCCTG cooperative group clinical research nursing board. She has published in the field of breast cancer research and clinical patient management in peer-reviewed nursing and medical journals. Frances today will be speaking on "Long-Term Survivorship: Understanding and Using Your Treatment Summary." Please welcome Frances.

### FRANCES M. PALMIERI, RN, MSN, OCN:

Thank you, Valerie. Wow, thank you. I'm so pleased to be here today. Thank you for coming

to my city. It's really great to have you here. It's going to be raining, so you're in the right place. Just stick here today. I see a whole lot of my friends in the audience, and I'm really happy to see you. To Valerie's point, I'd love, Jen, just to give a little wave from up front. Jen and I crossed the half marathon finish line together last Sunday. We're really happy to celebrate survivorship in that way with a big physical activity and an outpouring of love and support. When I saw over 8,000 women and men running across JTB Bridge as far as you could see from one end to the other, I said, "This is hope for all of us right here." I hope to impart that to you during your period of survivorship.

How many of you consider yourselves survivors? All of us are. At any stage and during any phase of your treatment and ongoing you are in a phase of survivorship that can only be determined by the way you feel, not the way others tell you you should feel and in what stage you think you should be. So I thought we would start out by figuring out what we should talk about today. I thought, "Wow, this is kind of a big topic," but I see there are so many topics to explore at this meeting. I'm really glad you wandered your way into this one.

Why is it important to maintain a summary of your breast cancer diagnosis, of your breast cancer treatment and your breast cancer care plan? Why is that important? What should actually be included in your treatment summary? How should you integrate your personal medical history into your current but also your future health plan? What are the current guidelines? What are people saying you should and should not do as far as breast cancer follow-up? I'd like to really treat these as discussion topics. I broke the topic along in your slides. You have copies of the slides, so don't go crazy making notes, but, rather, try to focus on discussing among ourselves. I'm a very casual speaker. Feel free to interrupt me at any time to ask questions or make a point. We'll try to keep

going to keep your time limit in place so you can get to your next session while trying to explore these discussion topics as best we can.

You should have four handouts besides copies of your slides, which would make five. [Note: handouts from this presentation can be found at <http://www.cancer.net>, which provides oncologist-approved information from the American Society of Clinical Oncology.] The first one looks like this. It's a rather simple sheet. It's two sided. That's going to look orange on all the slides. It's your breast cancer follow-up and management in the adjuvant setting patient flow sheet. The next one looks like this. It has a shaded area. It will always be in pink on your slides. This is your Breast Cancer Adjuvant Treatment Plan that ASCO has as a guide. We're going to talk about that. Then there's one, the next one, which is in green on the slides. That one is also the last of the stapled ones. That's the guideline update that ASCO just did. The last one is just a little resource list, although I think you could walk in the lobby and find all of these people that are actually on this list in your lobby. In addition, this is just a list of online and addresses and phone numbers for you regarding this topic.

We talk about this time of survivorship as almost a transition period where you're moving from that time of going through your treatment, having to learn a whole lot of new things at once, experiencing your treatment, your schedules with treatment, to then finishing your actual physical chemotherapy and maybe, perhaps, still having antihormonal therapy or going on with trastuzumab therapy. But it's a little transition time that melds one on top of the other. During that time we like to think that there is the potential to summarize your care, that acute phase of treatment—surgery, chemotherapy, radiation therapy, and now moving into this next area—to summarize what's happened and communicate to the people that you're going to interact with next



in the healthcare field about what transpired, what happened during your cancer treatment.

We hope that this survivorship care plan will allow you to describe both the known and the potential late effects of cancer treatments, and, with that, the expected time course for each of those expected effects. As you well know—I imagine a lot of you have all completed your therapy and that's why you're in this session—there are some effects that we just don't anticipate. They're not common effects. Perhaps they're less common or even perhaps unknown effects that may be learned about later as time goes on. Those can be added to your survivor care plan. This care plan also allows us to communicate to you, the survivor, and other healthcare providers what has been done and, quite frankly, what still needs to be done in the future for you.

In addition, this plan should really focus on how we promote a healthy lifestyle for you. One of the questions I get, no matter where you are in your trajectory of treatment within the breast clinic, is "What can I do to make myself as healthy as possible during my treatment?" But you also have to think about that afterwards. What can I do to keep myself at my very best? What can I do to now promote a healthy lifestyle off my treatment that will make me feel good and perhaps give me some control over what's happening with my body?

This is the perfect time for us to do surveillance, to watch for recurrence. We know that breast cancer survivors are at risk for recurrence, and we want to try to really look at that in terms of how we can first identify a recurrence. What are some of the symptoms? Sometimes they can be very occult or hidden, those symptoms, and we want to be able to have good surveillance while not pressuring you to have so many tests that are unnecessary or go through a lot of unnecessary stress, anxiety, distress and expense when it's not necessary.

In addition, we want to reduce the risk of comorbid conditions. I mean, not only is breast cancer a risk for us women. What are some of the other things you can think of that happen to you, perhaps as you age? What's something that comes to mind?

**MAN:**

Arthritis.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Exactly. [What are] other what we call comorbid conditions? Number one: heart disease. We as women need to be cognizant that we need to protect our heart. Some of the treatments that we may receive, such as certainly chemotherapies, perhaps certain radiation, may affect our heart function. There we have kind of a double whammy. You really want to be aware of your cardiac status, and you want to promote a healthy heart for the rest of your life.

Diabetes. That is a very frequently occurring comorbid condition that we watch for as we age, perhaps if we have a lifestyle that led to a higher weight, less activity. That [lifestyle] seems to be a really big trend, even among very young children in our school system right now. So when we survive breast cancer we want to look at some of these other healthy lifestyle factors that we can [use] to give us really good quality of life, because you are going to survive your breast cancer, and now you have to think about living the rest of your life.

There is early evidence that the family physician can provide quality follow-up breast cancer care with guidance. What we hope to do with this survivorship care plan is impact you as a survivor and impact all the healthcare providers, not only the oncologist and maybe the radiation oncologist, but the primary care providers. I know that a lot of us are able to go for cancer care to a specialist for perhaps a designated time, and then they want to turn you back over to your primary care physician. Sometimes insurance companies can dictate when that is. Often we can also be involved in that decision.

What are some of the key elements that we might look for here in this survivorship care plan? We want to make sure the plan allows for surveillance for recurrence or second cancers. We want to make sure that there is identified a primary or principal caretaker during survivorship. Right now, those of you that have been through therapy, how many appointments might you have [after] your immediate chemotherapy? The medical oncologist, your radiation oncologist, maybe your physical therapist, your nurse, a nutritionist? You may have varying members of the healthcare team that are following you. But we want to know who's going to be responsible for me now in my survivorship? Who is my coach now? I want to know that. This plan helps you to actually write one down. That doesn't mean it's written in stone.

That means it's written down as your first point of contact, and [you can] be flexible. Perhaps it may change as your needs change.

Psychosocial and vocational needs. You may not be able to or want to continue within the same job that you held previously. Maybe you want to do something different. Maybe you experience something in your treatment, in your diagnosis, in your care, that led you on another path, and you decided that you wanted to change your job. I had a patient who worked in mathematics and worked in Wall Street, but after breast cancer therapy she really wanted to go back and teach. There are ways to be ushered back into that kind of environment, whether it's going for online schooling or different things that you can do to meet your vocational needs.

Some of the other elements we might think about: preventative behaviors. We talked about cardiovascular disease and some preventive measures you could do, some interventions to get you up and moving and maybe exercising when you previously had not. I look at this transition as what I call, and those of you in the audience will laugh when you hear me say this all the time, a "teachable moment." I have many teachable moments every moment of my life, and I like to think all of us do. We can take this opportunity and say, "Okay, wow. I can change my lifestyle. I can do things a little different right now. I can look at health. I can look at wellness. I can look at preventative behaviors in a different way. I can document that on my plan." Once you write down a goal it's easier to break it down and get to those small, achievable goals, to meet that eventual big goal that you want.

Secondary cancer prevention. This is my bandwagon if I have ever had one. If you have family members who smoke, if you have daughters who smoke, tell them to stop. Coming from you this will have a great impact. We know from medical studies, research literature, that the healthcare provider merely mentioning to someone that they have the ability to stop smoking—it's called smoking cessation, a word you hear a lot—if you talk about it, it can be achieved. People are more likely to do a behavior if it's verbally mentioned to them. If you smoke, consider stopping now. Consider using resources to help you stop and influence all of those around you to stop smoking.

Weight management. This is something we all struggle with, and it is something that I hear over



and over again during treatment. I was telling a personal story. I was just put on a Medrol dose pack. Oh, my God, you guys who take Decadron or prednisone, whoa. It can really change the way you feel. You feel shaky. You feel jumpy. Just like, whoa, whoa, whoa all the time, but there's nowhere to go. But I've heard that that's a big problem with weight gain. So we take these medications sometimes to help prevent hypersensitivity reactions from drugs, sometimes to help us with our antiemetics, with the antinausea medicine. But they can have also these effects of weight gain during therapy. So you have in your mind, "Well, gosh, I ought to eat everything I can. I ought to get all the nutrients I can." Yet perhaps we're not eating the right things, and we gain weight. You think, "Well, gosh, I really went through this therapy, and that carrot cake with that icing looks really good, and I'm just going to have it because I deserve it." And I think you do deserve rewards all the time. But sometimes we have to have rewards other than food too. So weight management is one of the things you like to think about when you're in your survivorship plan planning. Try to think of that in terms of goals for you too, if it's one you would like to pursue, along with exercise. Exercise can be in many, many forms, and it all benefits you.

Some of the other very specific things that we look within on the care plan, some key elements are tissue diagnosis and stage, initial treatment plan and the dates of treatment. We're going to talk a lot more about this, and I'm going to show you exactly on the written form with the ASCO form as an example of how that can be done. The toxicities during treatment: on your care plan, you want to know what of these toxicities might be more long term. And within that long-term realm there's the short term and then the longer term of long term. These I should be concerned about in year one; these I should be concerned about throughout the trajectory of my survivorship. The required late toxicity monitoring, what things way down the road might I be interested in.

Id like you now to look at your handouts and pull out these first two. [...] We're really going to go through this step by step. When we look at this, this is all information that is going to start becoming logical to you. You can think, "Oh, yes. Yes, that makes sense." Don't be intimidated by all the information.

**WOMAN:**

My question is that your first bullet point says, "The first post-treatment mammogram should be completed one year after the initial mammogram that leads to diagnosis, but no earlier than six months after definitive radiation therapy." Why no earlier than six months after definitive radiation therapy?

**FRANCES M. PALMIERI, RN, MSN, OCN:**

When you have radiation therapy to the tissues of the breast, it causes changes that evolve over time. We can monitor that really on your imaging. We can watch it. It's amazing. I should have brought some pictures to show you, and next time maybe this is something we can do, is bring one of the breast imagers in. Your breasts continually change after therapy. We think you need about six months after radiation to the breast tissue. It's the breast imager who will decide when that tissue has stabilized.

**WOMAN:**

Can we go to the ASCO Web site and print these out?

**FRANCES M. PALMIERI, RN, MSN, OCN:**

Oh, yes. You can print these out from that ASCO web site.

**PATRICIA A. GANZ, MD:**

I'm really grateful to Frances for doing this, and she's doing a great job. But speaking as the developer and the leader of the ASCO Web site form, what we would really love is for you to print this out and take it into your oncologist and have your oncologist fill it out. Because my campaign is to get every oncologist doing this for his or her patients, because you deserve it.

If you go in to the doctor and say, "Have you heard about the treatment summary? Have you seen the ASCO treatment summary? Will you do it for me?" the doctor will do it. So that's what you need to do. I think Frances is going to tell you now what to do when the doctor gives it to you, hopefully. Go to the Web site and pull it down and give it to your oncologist to do.

**FRANCES M. PALMIERI, RN, MSN, OCN:**

[...] I wanted to make a point here that your oncology nurse can be very helpful. This is what I do. It's what we're trained to do. We just love it when you come to us with things and say, "Can

you help me?" I'm, like, "Yes!" Don't be afraid to do that even if it's been a year or two years since you've seen them. Just go back. It's perfectly acceptable to do that.

Now, what we're going to do is go through some of the forms so that you can understand them. As Dr. Ganz said, this is not your responsibility. But, as we know, knowledge is power. If you understand all these points, you can make everyone accountable to you. As it was said, you deserve that. So always remember, if you don't understand, ask.

The first one: this sheet I really put in there just so you could see what a kind of basic summary might be, something to take notes on. Right now you may have already gone through your treatment, but hopefully in the future if we can get everyone into this mode of treatment planning for survivorship, we can get all this started at the appropriate time, which is as you're experiencing it, when you have your first abnormal mammogram or palpate your first abnormal lump.

It's kind of a good worksheet. It gives you some basic information. First thing: start and end dates for all treatments. This is so important to us as healthcare professionals. Sometimes when a cancer recurs we want to know what exactly did you have exactly when and how many months [after] start of your treatment? What were the effects that happened? Why did you stop taking that drug? Was it not effective or did it make you throw up so much that we had to stop it? We need to know those things.

Things are easily forgotten years after the event, and if you don't believe that, every new patient who comes to me, we disintegrate into the conversation, "Well, do you remember four years ago when you got your treatment, were your drugs red or yellow? Were they hung in a bag or did you take them orally as a pill?" We kind of go back to that guessing game. If we really concentrate on doing some of this up front, not to bring up any bad memories when I mention colors, but we really want to know. "Okay, what were your total doses of certain drugs?" Adriamycin or doxorubicin, that drug? We want to know that total dose because we want to know how much you've had so that we can be within that range of safety for your heart. If you ever need that drug again we want to know how much you've already had. [...] "Oh, it's important for me to have a start and a stop date. I'm going to remember that."



One thing that's really cool is you know how people always ask in your treatment time, "Well, what can I do for you? What can I do for you? I want to do something." You don't want anyone else to bring any food to your house, especially when it smells, and you don't want to ask for certain things. But sometimes you have a caregiver with you who really wants a specific job. I find this to be a really wonderful thing to do for teenage children. Engage your children with you, if they're willing, and [have them] come with you especially for treatment, to help jot things down. It's a nice responsibility you can give them.

Let's look at the next paper. That's the one with the shaded areas. This is a very detailed tool. This is to be completed by your healthcare team at your transition visit. I have a feeling we're going to have many people that never had a transition visit. In my facility we hope that will never happen again. This information is very important. Your healthcare provider will fill out the top for you in the beginning. So you look at the beginning, and you see one up top here, that's page one. Two is the back of it. Let's start with one.

It gives the provider's name. It gives your name, your date of birth. Do you see that? Your age at diagnosis: This will be very important. I see that many of you in the audience with breast cancer are very young. We look at that age of diagnosis very critically in terms of the screening and monitoring of your daughters and sons. We want to know the age at diagnosis. We want some contact for you. We want contact information for your support people that's different from your contact information. [...]

Then we go to background information. If you look at that part, what the healthcare professional, whether that's your nurse practitioner, your oncologist or your physician, sometimes it's a resident who works with you, they're going to fill all this out. The first thing they're going to fill out is what is the site of your breast cancer? Exactly where is it? What is your family history? This is a really nice summary, as you can see, for you to have yourself, right? But it's their responsibility to fill it out for you.

Then it goes into the definitive surgery for your breast cancer. This is not the end-all, do-all document, but a very, very smart group of people got together to develop it, and I think they did a really great job. If it's not perfect for you and your circumstance—for example, you may not have ever had chemotherapy, and so that's irrelevant to you—

you can use this to determine what elements might be important through discussion. Bring this form, hand it to your doctor and say, "Okay, what is relevant for me on here?"

The physical and biological characteristics of the breast cancer tumor itself are very important. When we look at recurrence also we want to know what the biological characteristics were. What is the estrogen-receptor or progesterone-receptor status of this tumor? Does that sound familiar to you? What's the HER2 status of the tumor? We want to know. What are some of the physical characteristics? How large was the tumor when we removed it? How many lymph nodes were involved with cancer, if any were? Were there other areas where the cancer was involved? This section right here is how they fill that out.

Then they come to giving you a stage and a pathological stage. That plus the copy of your pathology report from your definitive surgery should be stapled together. Keep your original pathology report. Anyone should be able to give that to you. That puts you in control of that.

#### WOMAN:

Can you still access this information years after treatment ends?

#### FRANCES M. PALMIERI, RN, MSN, OCN:

Absolutely. You absolutely can. How do you get this stuff? [You could call the] [...] oncologist or the surgeon. Sometimes you can call your last practitioner, who would probably be your oncologist, and say, "Hey, I have this survivorship care plan. I'd like to come in and go over it with you." If your insurance will not allow you to do that, then what you may ask is, "Can I meet with your nurse practitioner or your oncology nurse and go over my records and fill this form out?" I've had people do that, and, I'll tell you, it's a bright and shining moment for me when that happens. Don't be afraid to do that.

You can also call the hospital or the clinic where your surgery was done and ask to speak to the pathology department. [...] When you talk to them, say, "I'm a breast cancer survivor. I had my surgery at your facility. I need a copy of my pathology report." A lot of institutions will not do that directly from the pathology department. They'll put you in touch with the medical records department and charge you five dollars a copy for every page. But do whatever you need to do to get it.

Then, if you need help in transferring the information from that pathology report to this form and you don't have a provider because it's been years since your cancer, let's say, or some other circumstance, I know that you can call Y-ME [now Breast Cancer Network of Strength, <http://www.networkofstrength.org/>], CancerCare [<http://www.cancercare.org/>], People Living With Cancer [<http://www.cancer.net/portal/site/patient>], and get assistance in doing that form with them. I would tell you it really is beneficial to sit down one-on-one, even if it's been years, to go over this with your healthcare provider.

#### FRANCES M. PALMIERI, RN, MSN, OCN:

There's also room for other diagnostic and baseline information about your health status. It's really important to know if you had heart disease going in to your treatment, for example. We would want to know that because, let's say no one knew that and then five years later you go see a primary care physician who says, "Wow, you have some heart disease; that must be from your chemotherapy," but meanwhile you had it even in the beginning. What I talk about is baseline. Where were you before you started your treatment? That's why this form is divided into this clearer area here and this shaded area here. This information kind of goes over where you were at baseline, at the beginning of the treatment phase. Then the shaded area looks more at after the treatment time. What is the summary of everything that occurred?

Documentation of menstrual status is very important. Again, looking out at the young age of this audience, we want to know were you premenopausal before your therapy and postmenopausal later? Or when did that status change? We want to know that, or if it did. Both chemotherapy and what we call biological therapy, targeted therapies like trastuzumab or lapatinib. Does any of that sound familiar to people here? Yes? No? There are other therapies besides drug therapies. Specific drug therapies are called chemotherapies, chemicals that we inject or are ingested in your body that combat the cancer. But there are also biological agents, targeted molecular therapies that attach to proteins in your body to also ameliorate the cancer or keep the cancer from coming back. There are two different kinds of therapies that we think about in addition to radiation therapy.

Also documentation of events during therapy: did you have a very severe allergic reaction to some



of the chemotherapy? We would want to know that, so that should be documented on this form by your healthcare provider. The radiation summary is generally given separately. Staple it to this form. It goes through how many gray, how much of a dose of radiation split over what period of time and what the total dose was. The radiation oncologists have been doing this very well for a long time, giving you a treatment summary. But they usually give it to the other providers, not to you. You can ask for that from your radiation therapist or from medical records again.

There is also an area on the back page. Look at page two. There's an area there for endocrine therapy, so if you're taking tamoxifen or an aromatase inhibitor there's room for documentation on that. There's room there, also, for this very important information regarding your contacts, not only your personal contacts but those people who actually did your treatment. Let's say that you're ten years out from therapy and your doctor wants to get a hold of your oncologist. Do you have contact information all on one sheet? You don't have to rifle through all those notes and things that you made to find that information out. Hopefully they're still in the same place and you can track them down, right? Again, it's important information that you can also provide to keep people in touch with you. Let's say there's been an advance or there's data from a clinical trial that you participated in. Many times they will ask for contact information.

The comments section here can be utilized for many different things, including additional health information, clinical trial participation, physical therapy, things that you learn from the nutritionist that you're going to maintain for your survivorship plan, psychosocial interventions, and reconstruction/plastic surgery. There are other areas for that, but maybe that's included in your ten-year survivorship plan, not your immediate plan for reconstruction.

I'd like to go to this other handout. This is looking at guidelines, because, along with a survivorship plan, what I hear very often is, "Okay, it's very nice for me to have a plan, but who in the world decided how someone was going to monitor me after my breast cancer? And shouldn't I be being scanned from head to toe every month?" We can all giggle and think about how incredible that is, but there's a lot of fear about cancer recurrence with breast cancer, and you want to do the right thing. You want to try to think, "What is the best thing

for me?" Well, a lot of people have looked at the literature and tried to come up with some guidelines. Now, guidelines are guidelines. They're not fact. They're not rules. They're not things that only can be adhered to. They're sort of a pathway for us to take. You may have very specific things in your care that need specialization, and your oncologist can certainly put that on your plan.

We know that care can be provided by your oncologist or your primary care physician provided there is communication between them about your appropriate follow-up plan of care. You don't need to be afraid to ask if they have spoken to them or communicated with them or read your plan. If they haven't read your plan you could say, "Okay, so I understand according to my plan I'll be getting my mammograms every six months or four years or every year until stabilization. Is that what you understand?" We use that kind of reflexive questioning a lot so that people won't just disregard your statement but have the physician try to engage with you a little bit about what's going on here. Again, use to initiate discussion. That means you have a copy of your plan. Not only was that plan put in your chart and filled out, but you got a copy of it. If you didn't ask for it, again, specific case surveillance may be required.

The purpose of this follow-up care that we wrote all these guidelines about is to help maintain good health after treatment, including coping with the side effects of treatment, reducing that risk of recurrence and watching for signs of recurrence. Visit your doctor. You need a history and physical examination and you need those regularly. How regularly that will be will be determined by you and your oncologist when you meet and talk. Generally it's annually. Sometimes it needs to be more often than that. What we say generally is every three to six months for the first three years after your first treatment, and then every six to 12 months for years four and five and every year thereafter. This is how it looks when you look at it in a grid, and it makes it a lot clearer than the words to look at that in that way.

Post-treatment mammogram—schedule a mammogram yearly. Make sure you have it if you still have breast tissue, but no earlier than six months after radiation. [...] You want stabilization of your breast tissue. The imagers and your doctors will help you figure out when that is. Sometimes it's a very long time down the path before they say there's been stabilization.

Breast self-examination: I know this is an area of controversy for a lot of people, but it isn't for me. Just like every other part of your body, be aware of your breasts. Look at your body. There have been changes, and you have to now get familiar with those changes. This is a long process for a lot of people. Some of my patients tell me this is a very painful process for them. They've changed their mind frequently as they've examined their body to say what's normal to them and what isn't. Be aware of how your breasts look.

Own it. Incorporate your body. Be proud of it. And when things change get right on the phone and let somebody know, and hopefully that's your healthcare providers, after you call your girlfriend and all your buddies here. If something changes, get checked. That means you feel something different. All of us heal in a different way. Sometimes we form a lot of scarring, and sometimes we don't. Sometimes you feel along that scar line and something really feels different. Sometimes it's just consolidation of the tissue, just normalization, which now feels abnormal. But if you feel a change, get it checked out. Be aware of your breasts. If you have breast tissue, examine your breasts every month.

**WOMAN:**

Should you examine your breast area monthly if you have had a bilateral mastectomy and do not have breast tissue?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Yes.

**WOMAN:**

I have lobular cancer that was very hard to detect on mammography, and I am going to be starting my radiation. Now, I'm just wondering if I should have an MRI before my radiation. I have one breast that was removed. Should I have an MRI on the other breast that's still there?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Her full question was that she has lobular cancer and that wasn't detected on mammography and...do you mind me asking you how it was detected?

**WOMAN:**

I had felt a lump. But the lump was there. It was misdiagnosed.



**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

But you felt something there, you could tell after in addition.

**WOMAN:**

An additional lump where the lymph node was in my breast. It spread to the lymph node in my breast and...

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

It formed a lump.

**WOMAN:**

When they took the MRI, it was all over the MRI, but it wasn't detected on the mammogram.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

This is a new technology, MRI, but, boy, it's really proved to be useful in a lot of cases. Unfortunately, MRI is not always better for lobular cancer either. Doesn't that just make you mad? That really made me mad because I was really hoping it would. But in some cases it does [help]. The person who can best decide whether an MRI is advantageous to you or not is the breast imager who looks at your mammogram and looks at your MRI that you had and decides whether the other breast needs to be scanned using MRI. Because what we see often is that lobular cancers don't really image very well either with MRI. But they're really high risk for breast cancer, maybe an indication for following someone with MRI. That doesn't mean you only have an MRI, because you always have to have a mammogram with your MRI, even in subsequent times.

**WOMAN:**

But in my situation cancer was all over the MRI and not in my mammogram. Then when they took an MRI on my left breast, they didn't see anything. But that was six months ago, before I started treatment. Now I'm getting radiation, so shouldn't I go back for MRI again on the left breast?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

If they really felt in your normal breast, what the imagers will do is look carefully at that tissue, and they'll determine how often they think it needs to be done. Those are the guidelines you follow for that.

**WOMAN:**

Because one of the things that I have learned from coming to this conference from the women I've been speaking with is that cancer has grown rapidly. Six weeks, and it grows.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Yeah. That's right. To your point, let me clearly say that this discussion needs to be with your healthcare providers. I can't answer that question for you. I can only say to you that careful clinical exam—that means a health provider giving you a breast exam on your normal breast or unaffected breast—and the use of good imaging together make the best plan for early surveillance. That's what they'll do for you. That together is the most important thing. Whether it should be done every six months, whether it should be done every year, it's really up to the imagers to look at that tissue and see how symmetrical and how confident they feel. They will help to determine with you what that pattern will be. You can actually talk to your healthcare providers and get to some kind of compromise with them on a one-on-one basis about what you should do for surveillance.

**WOMAN:**

How dangerous is it to have an MRI done? [Are you] getting a lot more radiation [than you should]?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

There are a lot of issues with how often to do tests. When we talk about the guidelines, they don't say to scan you head to toe after your breast cancer diagnosis. That surveillance does not lead to increased survival in patients. We came up with a set of guidelines that are good for overall screening. But if you detect any abnormality or any change in between your regular examinations, and that's why you go every three months, every six months, you're being constantly followed. You're not really in this realm of long-term survivors yet. You're in the more acute phase in that you're being constantly monitored. Once you go out of that, then we try for general surveillance and try to go with that and not have constant testing with constant distress. Because you do pay a price personally for doing a test and waiting for the results and, in addition, paying copays for tests that may not help you in any way.

Pelvic examinations—This is another place where you can have a big impact. Very, very often

what I find is that once you have breast cancer you focus above the waist. But we still have to think about what to do to monitor for cervical cancer and to continue to visit a gynecologist regularly who can palpate your abdomen and look for any other problems. If you're taking tamoxifen this can be a very, very particular area for you. Because we know that there's an increased risk of endometrial cancer with tamoxifen, we want to be sure that you're being monitored.

**WOMAN:**

Does a Pap smear check for endometrial cancer?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

[...] No. A Pap smear is actually where they look at the cells for cervical cancer. But as part of your routine gynecological exam they will palpate all of those organs in your abdomen and look for any abnormalities. When you have breast cancer at an early age, please tell your gynecologist that. Again, we look at family history, and we're going to talk about genetic counseling and screening a little bit later, but really there is that ongoing gynecological treatment that's very important.

**WOMAN:**

My question was related to hers. I was very surprised at my annual exam with my ob-gyn that instead of doing a Pap smear, I had been tested a year before for HPV, which luckily was negative, and so she said that is kind of taking the place [of the Pap smear]. They didn't do a Pap smear then. The HPV they did, and if you were negative for that you were fine. That alarmed me. I said, "Wait a minute. I'm a breast cancer survivor. I think I need everything." But she was, like, "No, no."

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

But she did a full exam?

**WOMAN:**

Oh, yes. Absolutely.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Yeah, and that's the important thing. Sometimes you will find, don't be surprised, that now we do a lot of transvaginal ultrasounds and different things to look at those areas and the ovaries and so forth.



**WOMAN:**

I always go back to the self breast examination thing. I've been out of my cancer treatment for 11 years. But for a long time after radiation, [...] there were a lot of changes in my breast. As a matter of fact it felt like it was swollen and very hard, and it wasn't like it went down in six months. I mean, it just kind of went down over the last year. So consequently, I guess what I wanted to bring to everybody's attention is, at least with me it was difficult for me to do [breast self examination] on that breast because there was a lot of scar tissue. Along the line where the surgery was performed there was a knot, and the very first time I felt that I was panicked.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

I'll bet.

**WOMAN:**

Of course I went to the doctor and said, "What is this?"

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Good.

**WOMAN:**

Even with my mammograms, though, they saw it, and they kept telling me, "Well, we think it's scar tissue." But there was never anything definitive about any of their answers. Every doctor felt it and was, like, "Okay, yeah, it's a hard knot here, but we just think it's tissue."

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

She really makes a very, very important point. I want to bring this up because not only is it you that's feeling an abnormal breast, but the doctor who is examining you should be proficient in palpating an abnormal breast. Do you see my point from her conversation? What if you just went to "Dr. Ob-Gyn" who never saw a breast cancer patient, and you show up with your breast, and he's like, "Oh, my God. You have inflammatory breast cancer." I've had patients come to my breast clinic like that.

[With] that good, careful surveillance, try to leap beyond the fear. It's so hard. You really want to just sort of molder in that. But try to get beyond that fear. Feel the abnormality. Understand it is [there], but it's okay, and just go on with it. It's going to be there. It's going to change every month. Understand that. You really will be okay, and you

will get through it, and one day you're going to have a breast that stops changing so much.

**WOMAN:**

I was diagnosed with lung cancer prior to the breast cancer. They're completely unrelated. But, as a consequence, I've had several PET scans, and I'm still unclear about whether the PET scan is able to detect additional breast cancer.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

PET scanning sometimes does actually reveal breast cancer. It's a typical screening tool that we use for patients when they've had early breast cancer and there's no evidence of disease. It's not very useful as a screening tool, but sometimes [it is used] in patients who, for example, develop lumps under the arm like you described. [...] Like she was talking about, where we want to look at the breast because we have another problem, and sometimes with PET scanning we can really see that in the breast. To answer your question, yes, it will image sometimes. You're asking because you have those tests all the time for your lung cancer, and you want to say, "Can I relax about my breast cancer?" Well, it's one more tool. Because you're having it for your lung cancer, yeah, you also have that, but it's not a typical screening test. We'll go over those non-recommended things a little later too.

**WOMAN:**

Can you explain bullet number two?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Absolutely, and we're going to talk a little bit more about that later, but we'll do it now because it's probably a perfect time now. [...] If you have an ER positive diagnosis, in other words if when they did the biological characteristics of your tumor, if they looked at it and said, "It's an ER or PR positive estrogen-loving tumor," they give you hormonal therapy to try to create a more hostile environment for the tumor, not allow that tumor perhaps to survive. We have clinical studies that show certain drugs like tamoxifen, aromatase inhibitors. . . you've heard of some like Aromasin, letrozole, anastrozole, Arimidex. . . have you heard of any of those drugs?

Only this one drug, tamoxifen, carries with it a very small risk of endometrial cancer. They found that in the large population of patients taking tamoxifen, there was a small increase of endometrial cancer diagnosis in some of those

women, so they're followed very carefully. You're going to see later when I put up a slide for things to look for, signs and symptoms to be aware of, if you're taking tamoxifen and you have abnormal bleeding, that would be something to report.

**WOMAN:**

What is the difference between [normal and dangerous] vaginal bleeding. . . in someone who's not had a period for many years? How do you know the difference in what to watch for?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Dr. Ganz, do you want to. . .

**PATRICIA A. GANZ, MD:**

There is a difference. You are all young, and many of you who are still menstruating, and the case guidelines were written for the [inaudible].

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

For the whole population.

**PATRICIA A. GANZ, MD:**

Many younger women taking tamoxifen will just bleed regularly and you won't have anything remarkable to report to the doctor.

**WOMAN:**

I'm someone who doesn't.

**PATRICIA A. GANZ, MD:**

If you were to have new bleeding, new onset bleeding, it could be your periods are just coming back.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Yes, which they do.

**PATRICIA A. GANZ, MD:**

Or you could have something going on. In a regular postmenopausal woman who's never had cancer, if she has been free of menstrual periods for more than a year and starts to bleed, she also needs to go to the doctor because she could have endometrial cancer. It is a warning sign for endometrial cancer. It could be just that your periods are coming back. But it needs to be investigated, so you don't just say, "Oh, I finally got my period back," if you haven't had a period in over a year.



**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Do you hear the theme here? If something changes, something abnormal, get it checked. Right?

**WOMAN:**

One comment I wanted to make: I'm a one-year survivor. I'm also a nurse practitioner. I know when my breast cancer was diagnosed it was not palpable, so it was less than one centimeter. The initial physician that I went to for the surgery was going to do just a lumpectomy, but because this was just a general surgeon, I opted to go to a breast surgeon that dealt only with breast cancer patients. She looked at previous mammograms that I had, and it showed dilated blood vessels, but when you followed it, it just went to nothing. So she opted to go ahead and do an MRI.

When she did the MRI, it showed three additional cancers in the breast, and then it also showed a cyst in the left breast. It was helpful to me because based on that I would have had the lumpectomy and the radiation prior to knowing this. But the tumors were so small they were only picked up with the MRI.

I'm not saying that MRI is good for everyone, because it does have some false positives. Then you look at the possibility that you have biopsies to do that cannot be biopsied because some of them were so small, it was like two millimeters, where they couldn't even biopsy something as small as that. But I think it's a benefit if you're seeing someone who deals specifically with breast cancer as opposed to just general surgery.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

That applies to a diagnostic clinic overall, because there are experts in that for a breast diagnostic clinic. We're running a little tight on time, but I want to make a point to your point. That is that we have to differentiate between this testing for diagnostic strategies versus long-term surveillance. You have to be very, very clear about that. How you get to a diagnosis and the tools and the imaging we use can be amazing. With surveillance we use all of these tools when they're needed. Now, for your case MRI was very beneficial, so you might want to ask if no one has ever approached you for an MRI and you're in that diagnostic strategy even with a recurrence if it could be helpful to you. That's an excellent point.

Coordination of care. As you go through this transition, your care may be transferred to a primary care doctor or you may want it transferred back to your primary care doctor. We know that risk of recurrence continues even when there's no evidence of disease. We want to make sure, again, that the physician you're going to is experienced in the surveillance of cancer patients and experienced in breast exam. We said especially if your breasts are irradiated that they understand the treated breast.

Women who are receiving hormone therapy should really talk to their oncologist during this session where you're filling out your plan or if you're doing it later to say, "How often should I see you, my oncologist, about this hormonal therapy that I'm taking?" if you're still taking it when you were sent back to primary care.

Genetic counseling referral is very important. Review your family history. You saw that even the form has a space for that, so make sure you let them know if you have any risk factors that run in your family. Within here it kind of delineates what's first degree and second degree.

**WOMAN:**

I'm just wondering, I'm almost four years out now, and I so far haven't gotten any of the genetic testing. Do you think that it's still important for me to do something like that?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

I can't comment on what you should do, but look at these risk factors on this screen. What do you think?

**WOMAN:**

[Inaudible]

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

If you feel it's indicated, you should really talk to your oncologist and talk to them about it and say you would like to even just speak... even if you think it's not indicated, say you'd like to speak to a genetic counselor. That doesn't mean you have to have genetic testing or any kind of testing. It means you should talk to one. They're so great because they really will go through all these risk factors for you, give you an idea of what they think your risk is and what your family members' risk is. You'll feel a lot more comfortable. They'll help you make a decision whether testing is for you or not, along with your doctor. They are a key person.

**WOMAN:**

If you have very few female relatives, which means you don't have a lot of breast cancer in your family, still consider going for genetic testing. I have an aunt and a grandmother that died, and that was all family on my dad's side, and I tested positive. I really had to fight to get my test done.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

But, see, here: any first-degree relative. Any. And you had first-degree relatives, so your mother ...

**WOMAN:**

No.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

I'm sorry?

**WOMAN:**

Paternal grandmother.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Paternal side. But half of your genes come from the male side, right? [...] It's not just your mother. You get your genes from both, so really look at your whole family, not just your mother. Can breast cancer happen to men?

WOMEN: Yes.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

Can other cancers happen to men?

WOMEN: Yes.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

You can see them in families. We see them spread throughout: colon, pancreatic, melanoma, all kinds of cancers that can happen in the family. If you have any question, talk to your doctor about it. If you'd like to speak with a genetic counselor, believe me, you don't have to have a high risk to do that. You could speak to them anytime.

**WOMAN:**

If you test negative for BRCA1 and 2, what does that tell your children and your grandchildren?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

That you didn't have the BRCA1 or 2 gene. That's all it tells you.

**WOMAN:**

But that means that ...



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### **FRANCES M. PALMIERI, RN, MSN, OCN:**

That's all it tells them.

### **WOMAN:**

It tells them that they did not inherit ...

### **FRANCES M. PALMIERI, RN, MSN, OCN:**

No. It just says that they didn't get it from you. I think that's an important point. I would urge all of you that have these questions to speak with a genetic counselor. It is a very, very complex and involved topic that we cannot get into in a short period of time, because there are many nuances of understanding this. I would urge every one of you to speak to a genetic counselor. It will make you feel a lot better.

### **WOMAN:**

I wanted to say the vice versa. She said I didn't have the gene, and I just wanted people to remember if you did [genetic counseling...], it doesn't mean that [your kids] are going to have it either.

### **FRANCES M. PALMIERI, RN, MSN, OCN:**

That's right. Yeah, so I would really urge you if you have any question about this and you feel it would help you to go to a genetic counselor.

This is the most important slide that I wanted to go over with this group, so I really wanted the time to look at this. New lumps in the breast. Report it. Bone pain, chest pain, abdominal pain; it sounds like everyday life, doesn't it? (Laughter) Especially if you start on an exercise program or eat too many desserts here at the meeting. Persistent coughing, rash on the breast, nipple discharge. Sometimes I've heard from people, "Well, it wasn't bloody." But you know what? Report all of these things if they're bothering you, even persistent headache.

[Some] tests that are not currently recommended and need individual planning no matter what for your care plan. [A] yearly physical exam [that] may include blood tests [is recommended]. [The blood tests are] not indicated just because you had breast cancer, but normally they're done as part of your regular physical, which is a complete blood test that includes liver and kidney function tests. Chest x-ray, bone scan and liver ultrasound are not recommended, unless they're indicated for a certain reason. [Also not recommended for regular follow up are] CAT

scanning, PET scans, MRI or tumor antigens, [...] tumor markers as they're called. Have you heard of [tumor markers]? Because they're not 100 percent. They're just not reliable enough for us to really say [tumor markers] can detect a recurrence.

My point to this is: you have now this word "ASCO." You can go to the ASCO site. You can go to any of the advocacy network sites. Because when these guidelines change, they make big news so that you can get regular information that you can go over with your physician.

These are some questions that you can ask: What overall follow-up care plan would you recommend for me? Are there special issues related to my treatment? What is the risk of my breast cancer recurring? I get that question all the time because people say, "I don't want to ask my doctor." Ask your doctor. (Laughter) It's okay. If you're ready to hear that, if that's something you want to know, well, that's up to you. Ask. Based on my personal and family history, do I need referral to a genetic counselor? This is a major question here. How can I find out more information about follow-up care? Are there additional symptoms based on the treatment I received that I should watch for? What are some of the common side effects of my hormonal therapy? How often should I return to you, the oncologist, for visits while I'm on hormonal therapy?

We said, "Why doesn't everybody do this?" Barriers do exist. There seems to be a lack of appreciation for the need and the value added. You guys could have a really big impact on that. Lack of healthcare provider time and reimbursement. A lack of awareness that survivors and primary care physicians actually need improved communication. Just like anything else, until you admit there's a problem no one realizes there's a problem. Limited survivor demand.

What do we need to do now to perhaps change this paradigm and promote the use of it? Well, first of all, to accept breast cancer as a chronic disease with an initial period of very complex treatment. It's integrated among many disciplines and needs follow-up. Ownership of this plan by specific interest, whether that's you as a survivor or your primary care doctor or your oncology nurse, someone needs to own it for you. Survivorship training is something that's going on a lot now, and it's really, really exciting.

How can this plan be used? At the end of treatment for discussion and specific recommendations, for formalization of this coordination of your care, and as a communication tool for everyone involved in your care, both your past care and your future care, so you can tell your health story. Sometimes a survivorship clinic is the right place for you, and we're developing one at Mayo Clinic, and I'm really happy to say that we have full go-ahead. It took a year, and we're going full steam ahead with a breast cancer survivorship clinic within our breast clinic. It's our same breast clinic providers that are specially trained in survivorship issues that will be manning this clinic.

The rest of this I can let you see in some of your slides, because it goes through what some of the important things are for us. Please take a moment to look at your resource list and see what things you can also look at to give you more information. I thank you so much for your time and your great questions. (Applause)

### **VALERIE KRAUS:**

We have ten minutes left for any additional questions.

### **WOMAN:**

[...] For a patient that's 25, [and] she's on tamoxifen for five years, would you shut down her ovaries?

### **FRANCES M. PALMIERI, RN, MSN, OCN:**

Sometimes when you've been on tamoxifen for five years your ovaries do shut down. But sometimes that's a long process. Some of the function is suppressed. That's really a conversation you need to have with your oncologist. Me as a stranger from the outside who looks at your case can't possibly recommend that to you based on your own risk. I don't know anything about your cancer or you. That is a personal decision, and there are lots of places you can go for additional information. I also encourage people that if you've had this conversation with your oncologist or not and you want a second opinion, you should have a second opinion. Sometimes that helps you to understand the issues a little better and try to understand what you actually think.

Dr. Ganz, what do you think about that kind of comment?



**PATRICIA A. GANZ, MD:**

I think what Dr. Partridge was talking about in her presentation, the SOFT trial is going to answer whether it's better to have tamoxifen...

**WOMAN:**

I saw a bunch of ovarian suppression in that.

**PATRICIA A. GANZ, MD:**

Yes, but it's a research trial, and so I have patients on it. She has patients on it.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

We won't know yet.

**PATRICIA A. GANZ, MD:**

We will have an answer. For you it doesn't help right now. But the standard of care for you is tamoxifen alone. That's why that's what you're getting. But when that trial is finished we'll have answers for future women. I'm sorry about not answering your question.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

I think that's a really good point. Any opportunity that you have to participate in survivorship studies, it's one of the reasons we really wanted to have a survivorship clinic, so that we could have everybody together and give access to those kind of trials. If you have the opportunity to participate in those, please consider them.

**WOMAN:**

I have a question for you. I just transferred to a different oncologist due to insurance. I was on tamoxifen for either three to four years, and now I was put on Arimidex by my other oncologist. He took me off it and put me back on tamoxifen, even though my signs showed that I was postmenopausal, and the last one he said it was a little bit above border. I thought this sounded good to me. He said because when you were on tamoxifen you were pushed into early menopause anyway, so we don't even know if Arimidex really was working for you. So he wants me back on tamoxifen. What do you feel about that?

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

I know that tamoxifen is the standard for women that are premenopausal. It's kind of a long trajectory to go into menopause and that measurement of menopause. So that is typical treatment.

**PATRICIA A. GANZ, MD:**

I have a slide in my talk, if you come to it in the next session, which shows that actually tamoxifen does not push you into menopause. If you get chemotherapy and then you get tamoxifen you may have an earlier time going to menopause. But what Dr. Partridge talked about was the fact that you're not truly in menopause. You may not be menstruating. You may still have your ovaries functioning to some degree. If you have any ovarian hormones coming out, the aromatase inhibitors don't work. The aromatase inhibitors only work when you truly are postmenopausal with hormone levels that are less than 20 estradiol. If you're making anything from your ovaries it doesn't work because aromatase inhibitors work by preventing the conversion of a male hormone or adrenal gland hormone to estrogen in the fat tissue.

It's just a very low level of estrogen. It's taking your level down from 15 to zero. But if your ovaries are giving you a level of 20 or 30 already, the aromatase inhibitor does not have any role to play. So you're not truly postmenopausal very often in this situation, and that's why she talked about the fact...remember the anecdote she gave of a patient of hers who had been switched to an aromatase inhibitor? She didn't come in for a blood test. She felt good again. And, lo and behold, she had a period.

**WOMAN:**

As a nurse, I want to just remind patients if they're feeling something they need to do a mammo and an ultrasound. So many times the doctors just order mammography, and they really need both.

**FRANCES M. PALMIERI,  
RN, MSN, OCN:**

There are two kinds of mammograms, and I would think you've probably experienced them all in this group. There's a screening mammogram which if you've had breast cancer you will probably never have again. But a diagnostic mammogram, and then sometimes if abnormalities are seen depending on what they see on the mammogram, the imager may recommend ultrasound. Sometimes they do not. But that is a useful tool.

**WOMAN:**

I just wanted to actually ask you, Dr. Ganz, how often do you estradiol or FSH test on someone who's on Arimidex? Forty-four years old, premenopausal, but then chemo put you into menopause.

**PATRICIA A. GANZ, MD:**

Again, this is based on experience actually with women on tamoxifen before Arimidex was even used in postmenopausal women. Women I would see who had been on chemo, [would go] on tamoxifen [and] two or three years later their period would come back. That is the natural history for a young woman who has what we call transient amenorrhea from her chemotherapy. She's not truly in menopause. The tamoxifen may mask that a little and make everybody think, oh, yeah, she's in menopause. The standard rule, which is that you are menopausal if you haven't had a period for a year, only works if you're above 50 and that's the normal time you're going through general menopause. [...] If you are taking an aromatase inhibitor, your estradiol level should be undetectable. It should be down near one or two. If it isn't, you're not getting the benefits of that therapy.

[...] Find out what that level is. The trick is that if you draw normal estrogen and send it to the lab, the labs will say "less than 15" or "less than 14." You don't know if it's 14 or one. In postmenopausal women whose normal estradiol level might be 15 when they stopped menstruating, we take it from 15 down to zero. If you were not truly postmenopausal and your ovaries are still putting out anything, you're not getting the benefits of the zero estrogen, which is what the aromatase inhibitor is supposed to do. That's why it's a very, very tricky thing to give somebody who's still in the premenopausal years and isn't clearly postmenopausal. Tamoxifen is still a really good drug.

[...] Many people have been burned with women essentially being switched over. The medical community is very fickle. They'll hear that aromatase inhibitors are the next best thing to sliced bread and if you are postmenopausal you need to use that as your first-line therapy. But I can just tell you there are plenty of postmenopausal women who cannot tolerate the side effects of AIs, and we put them back on tamoxifen. It's a drug that we know the good, the bad and the ugly: 30 to 40 years, long-term effects, etcetera, etcetera.



And it's very safe in younger women. We do not really see a substantial increased risk of endometrial cancer in younger women who still menstruate.

It's a tough area. Like a lot of the other things that were talked about, this is a very nuanced area. If you're just seeing an oncologist who sees everything in their practice, they're going to try and treat everyone who's postmenopausal the same way, and they don't think about it in the same way. If you come to somebody and that's all they do is breast cancer, if they're like me, I'm only really focused on the endocrine therapy, or Dr. Partridge on younger women, you're seeing somebody who's so specialized. They know this nuanced stuff. It doesn't mean your oncologist isn't good.

They're just treating lung cancer, colon cancer, breast cancer, lymphoma, and they kind of say, "Yeah. You're postmenopausal now. This is what we should do." But those of us who that's all we do, we know that this is the nuanced issue. I think when you're hearing this mixed message, it's because a generalist as an oncologist just can't necessarily know all of this, so you're getting informed and you're hearing about this here. Maybe that's something that Living Beyond Breast Cancer and the Young Survival Coalition might [recommend], so that you're all well informed and you're involved in the decision making.

**VALERIE KRAUS:**

I would like to just take a second and thank Frances for her very informative presentation. (Applause). Thank you.

[END OF TRANSCRIPT]