

“Am I A Survivor?”

What You Need To Know Now About Breast Cancer Survivorship

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Presented by:



SHARSHERET
Your Jewish Community Facing Breast Cancer

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I. Introduction, Defining Survivorship, and Unique Needs of Jewish Breast Cancer Survivors.

Rochelle S: Thank you all for joining us this evening as we present the teleconference, *"Am I a Survivor?" What You Need To Know Now About Breast Cancer Survivorship*. I am Rochelle Shoretz, the Founder and Executive Director of Sharsheret, and a two-time breast cancer survivor. Sharsheret is the Hebrew word for "chain" and it's a national organization that supports young Jewish women facing breast cancer.

I'll soon have the pleasure of introducing our distinguished speakers, who will share their insights into what has become a critical subject for those affected by breast cancer - survivorship. I want to take this opportunity to welcome all of you calling from different time zones. We actually have participants from 37 states and four countries, and many more are certain to join us as a transcript of the teleconference remains available online after tonight's presentation.

I'd like to begin by thanking the Federal Centers for Disease Control and Prevention for the grant that enabled Sharsheret to develop *Thriving Again*, a program to support Jewish breast cancer survivors. In developing this program, we spent a year speaking with more than 1,700 of you in person and through surveys, about your needs as breast cancer survivors. Interestingly, the first question most of you asked us was, "Am I really a survivor?"

Twenty four percent of you felt that you were a survivor when you were first diagnosed; another 28%, when you completed treatment; 25%, after your first anniversary with no recurrence; 13% of you told us, you don't consider yourself a survivor yet, and perhaps gave us a life milestone as to when you would feel like one; and 9% of you told us you felt you were a survivor even in the midst of treatment. Wow! That's a wide range of responses to an important question about the timing of the survivorship period, and one that raises a host of other questions that are being explored now in research studies and survivorship clinics.

With more than 2.9 million breast cancer survivors in the United States alone in 2012, survivorship research and programs like ours will play a critical role in cancer care in the years ahead. In developing Sharsheret's new survivorship program, we also learned that you had questions about transitioning from treatment to care after treatment. You wanted to know more about what you could do to safeguard your health and you wanted to

connect with others who may be experiencing the same concerns as breast cancer survivors.

Tonight our speakers will address those questions and more, and we'll introduce you to *Thriving Again*, Sharsheret's new survivorship program, so that you can continue to connect with us and other survivors throughout your breast cancer journey. I'll lead us off tonight by sharing a bit about my own survivorship journey, and some of the unique challenges of addressing survivorship as a young Jewish woman.

When I was diagnosed with breast cancer 12 years ago, I became obsessed with the calendar. I counted the weeks between surgery and treatment. I counted each day of radiation. I counted the months until I no longer had to renew my prescription for Tamoxifen. I spent hours wondering when I could actually count myself among the thousands of breast cancer survivors in the world.

Looking back, I understand that what I was really trying to do with all that counting was to put cancer behind me. I've learned slowly that it's much more important that I learn to walk comfortably with the cancer experience at my side. Well, that's easier said than done, especially when there has not been a clear roadmap to survivorship.

I don't know how many of you had a chance to read today's Wall Street Journal, but there's a piece in there about rehabilitation for cancer survivors with a great quote from Dr. Kathryn Weaver. She writes, "When cancer patients are diagnosed, everyone sits down to look at the case, decide what to do and convey that plan to the patient. But the same sort of process doesn't happen to survivors of the treatment."

When do we become cancer survivors? Some will say it's the day we're diagnosed with breast cancer. Others will say, it's the last day of active treatment. Still others will say survivorship is a mindset, the time at which you view yourself as a survivor of the disease.

For those like me, who are living with metastatic breast cancer and still undergoing active treatment, more questions arise. Are we ever considered survivors of a disease for which there is no known cure? What, if anything, do we need to understand about survivorship if we don't consider ourselves a part of this conversation? And how do any of us down the line reconcile the term "survivor" with that persistent voice in our head that often whispers, "It's going to come back; it's just a matter of time."

Discussing the definition of the survivorship period with your health care team, whether it's your oncologist, your nurse practitioner, a social worker, is the first critical step in managing that voice and then understanding your needs as a breast cancer survivor. Twelve years after my diagnosis, I still discuss concerns and fears with my own medical team. Keeping on top of emerging research through Sharsheret and other cancer organizations also helps me mitigate the anxiety of survivorship. Connecting with other long-term survivors through Sharsheret helps me understand that I'm not alone, that in fact there are thousands of other young survivors with some of the very same questions and concerns that I have.

Though there may not be a clear consensus on the answer to the question, "When does the survivorship period begin?", there is certainly agreement that it is never too early to begin thinking about issues of survivorship. From the moment we are diagnosed, through treatment and beyond, we should be asking questions about fertility, bone health, nutrition, and exercise. Starting that conversation can be as easy as asking your own doctor, "When am I considered a survivor and what do I need to know about survivorship?" The Thriving Again program we've developed at Sharsheret will help guide you in starting those conversations, no matter where you are in your cancer journey. We'll talk more about that program later on in the call.

For Jewish women, identifying as a breast cancer survivor can take on a host of other unique concerns. Not long after I founded Sharsheret, a reporter from the Wall Street Journal called to discuss survivorship and asked me a question that caught me off guard. She wanted to know if the term "survivor" was more troubling to Jewish women who may associate the descriptive term "survivor" with someone who has lived through the Holocaust. We've heard that concern from a few of the women who called Sharsheret. One in particular described feeling uncomfortable calling herself a survivor because her own mother had survived World War II, and she had heard so much growing up about what it's really took to be a survivor.

In truth, concerns about the term "survivor" seem to stem less from a place of Jewish history and more from a sense of Jewish superstition. Whether you call it an "evil eye" or "tempting fate," some would rather not call themselves survivors lest some higher power come to deny them that status. Better not to embrace the term and to transition quietly into survivorship.

For other Jewish women in the Orthodox or Hasidic community, breast cancer can often be taboo, something shrouded in secrecy, and the survivorship period, therefore, continues in secrecy. Discomfort with the

term or state of survivorship can be difficult today. We live in an age of breast cancer races and walks, pink products everywhere, and celebrations of survivorship by cancer organizations worldwide. As survivors, we need to be mindful that the survivorship period may, at first, bring with it more questions and concerns than pink balloons and celebrations.

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

Beyond prayer, I'd like to touch on some of the unique ways in which breast cancer affects the Jewish woman, particularly, in the survivorship period. First, using the mikvah, or ritual bath, can be a time of renewed healing. For some, immersion in the mikvah is a custom associated with marriage that can take on added meaning after surgery and after treatment. Using the mikvah can also be a time to embrace new traditions as the waters, and all they symbolize, bring hope for health. For others, immersion in the mikvah can force a confrontation with body image and sexuality. It can be a trying time, a difficult time, particularly as discussions about intimacy and body have been ignored during the hectic days of active treatment.

Wearing a wig or a hat beyond active treatment can raise a second series of concerns for the Jewish cancer survivor. Many assume that wearing a wig or hat might be easier for those observant Jewish women who covered their hair after marriage. Covering your head because you've embraced a positive religious ritual is very different from covering your head because you've lost your hair to cancer. For single women who cover their head during cancer treatment, doing that which is traditionally associated with marriage only complicates already complicated emotions.

Many young Jewish women living beyond breast cancer struggle with hair-covering. For some, wearing a wig post-treatment can be a painful reminder of cancer, a continuation of the struggle to cope with the side effects of a traumatic diagnosis. Others find added meaning in the ritual and choose to cover their hair with a deeper appreciation for its inherent beauty.

Perhaps, one of the most urgent subjects for the young Jewish survivors that we hear from at Sharsheret is fertility and the related concerns about parenting, both of which have a tremendous emphasis in the Jewish community. For those survivors who remain fertile, the decision whether or not to have children after breast cancer often adds another dimension to the anxiety of survivorship. For those with cancers that were hormone receptor-positive, fears of recurrence are triggered at the mere thought of the hormones coursing during pregnancy. These are fears that are played out over and over again for young Jewish survivors, fears that add another dimension to Jewish milestones like weddings and bar mitzvahs, when many cancer survivors are likely to think, "I hope I live to see this moment, too."

These are fears that way heavy during Jewish holidays, particularly during The High Holy Days of Rosh Hashanah and Yom Kippur, which trigger serious introspection about matters of life and death. At the same time, these Jewish milestones and these Jewish holidays can be a time for celebration, for affirming life and embracing the challenges of survivorship.

We are fortunate to live at a time when the discourse about survivorship is ripe. Tonight, we are proud to be a part of that growing conversation and grateful that you're here with us to contribute to it. With that, I'd like to introduce our first speaker, Dr. Jennifer Klemp. Dr. Klemp is graciously substituting for Dr. Patricia Ganz on tonight's call. Dr. Ganz had a family emergency and apologizes for not being able to participate. Thank you so much Dr. Klemp, for being with us on such short notice.

Dr. Klemp is the Associate Director of the Cancer Survivorship Center at the University of Kansas in Kansas City. She was recently invited to serve on the National Cancer Survivorship Resource Center's Quality of Life Survivorship Program and Navigation Workgroup. She has a clinical research interest in understanding breast cancer risk and cancer genetics, lifestyle modifications targeting cancer risk reduction, and improving quality of life, and the delivery of cancer survivorship care. Tonight, Dr. Klemp will address your questions about transitioning beyond active treatment, managing the fear of recurrence, and steps we can all take to maintain a healthy lifestyle as survivors. Welcome, Dr. Klemp.

II. Transition from Active Care and Healthy Living As A Survivor

Dr. Klemp: Thank you very much Rochelle, for that warm welcome. Thank you to all of you who are participating in this conference tonight, and to our hosts at Sharsheret, as well as my colleague and friend, Lillie Shockney. I want to build on Rochelle's wonderful definition and the complicated nature of "how do we define survivors?" I think that this constantly impacts our patients, but from a provider's side, it also causes some issues with transition. When we talk about cancer survivors, as providers, we do consider survivors from the time of diagnosis. However, I think that often gets complicated with how we deliver what we call "survivorship care."

The Institute of Medicine, which Lillie will talk about a little later, has defined the role of survivorship, and also how we compartmentalize survivorship care. I think if we talk to women at the time of diagnosis and treatment, survivorship care may look like education or prevention so that we can prevent possible side effects or long-term effects downstream.

Some of those examples, I'll talk a little bit more about, but they may include things like "energy balance"-that's the friendly term we use for diet and exercise. We may want to help educate you on lymphedema prevention, especially if a patient had a lot of lymph nodes removed. It's very important to talk about some of the psycho-social and coping strategies that are very important as you go through your cancer journey.

When we talk about the patient who is now transitioning from active acute treatment, into post-treatment care, that is often times where survivorship care is really defined. I can give you an example from our clinic. I opened our center in 2006 and it is a multidisciplinary clinic. I spent years building a landscape so that we'd have collaborators in cardiology, and fertility preservation. Survivorship really needs to look like that inter-disciplinary team because there are issues that may arise both from the diagnosis or treatment, but also there are often complications that our patients come into that diagnosis with.

If you think about our average breast cancer survivor, at least in Kansas City, I think it's different on some of the coasts, but we have a lot of our patients who are already overweight or may have weight control issues. You think about issues related to diabetes or hypertension or other cardiovascular risk. Our patients are complicated when they come into the diagnosis. Other patients don't have those complications so that lends to that personalized approach as to how we deliver survivorship care and then we need to have that infrastructure in place to help deliver that care.

Lillie is going to explain more about that more comprehensive structured delivery of care, in a few minutes.

The last part of the delivery of this survivorship care has to do with our patients, as Rochelle pointed out, who have advanced metastatic disease. I think we've often compartmentalized our metastatic patients and have not provided them with the same resources that may be available to patients with earlier stage disease. We've recently done some additional focus groups to better understand what types of targeted issues were unmet by our metastatic patients.

I think some of the key factors that have impacted how we deliver care had to do with things like sexual health and wanting to have intimacy and how do we re-define intimacy? It also had to do with "how do I function in my day to day role?" Also, how do we keep active and try to stay as healthy as possible? I think it's very important to think about survivorship care at all points of the continuum, from the time of diagnosis and treatment to when we transition from active treatment into post-treatment care, and then also, for patients who are dealing with a more chronic stage of disease.

The other important issue where I think survivorship plays such an important role is that as many of you know, because we keep reading in the newspaper every time we have a large national conference, we extend the amount of time that our patients are exposed to anti-hormonal therapy. This is a very important issue with adherence or helping our patients stay on their drug as directed so it can help, not only improve their outcomes, but it's our job to help our patients manage some of the side effects that may arise from these drugs.

As you can see, survivorship isn't, once again, a defined time point. I think it really needs to be considered across the continuum of care, taking a personalized approach to your needs, and trying to meet those needs with a multidisciplinary approach.

Talking just a little bit more about some of those side effects, I want to give you two different terms. There's the term you'll read called "long-term side effects" and then there's the term called "late side effects." I do want to give you a little bit of differential between those two because it doesn't mean we necessarily treat things any differently, but it does make a difference in your health care so you can look for some of these side effects, and then what should you expect downstream as a result, not only because of our natural aging process, but because of some of the treatments that you may have been exposed to.

"Long-term side effects" are things that may happen during the diagnosis and treatment. If we think about surgery, maybe that can cause some scar tissue and some pain. We may have risks of swelling or lymphedema. We can also have fatigue, loss of fertility, changes in our cognition, and those effects, may persist, even once the treatment is done.

"Late effects" are things that may happen to you downstream. I'm sure many of you have heard that some of the effects that some treatments we give can increase the risk for things like cardiovascular disease, maybe a little bit of weight gain. If we can better prepare and educate our patients up front for some of those late effects that they may be at increased risk for, then not only are you empowered to be part of the process, but we've better prepared you for managing or preventing some of those late effects so that you're looking out for those early symptoms so we can intervene as early as possible.

As you can hear from some of my messaging, I'm a very altruistic person, but I do believe that you, the patient, is the center and the only focus of control. You have to be part of the process from the time of diagnosis, all the way through your journey. That means asking questions, and that means making sure that you're using your voice.

The last part that I've been asked to talk about has to do with healthy living. I used the term "energy balance" earlier, one of the terms that is used in the literature, but our patients also appreciate that term because they think it has a little more hopeful feel than "weight management" or "diet and exercise."

"Energy balance" really has to deal with getting you back in balance. Obviously, that has to do with keeping you moving. It has to do with what we eat and how our body is able to process that. There are some basic guidelines that we talk with our patients about. The American Cancer Society, as well as other organizations, summarize these very nicely.

The first is they want us to achieve and maintain a healthy weight. We know that's important for all of us, but in particular, weight and what's called BMI, (a calculation of our height and our weight) that is a risk factor that's associated not only with things like diabetes, cardiovascular disease, and other chronic illnesses, but there's also an association for developing an initial breast cancer as well as for recurrence. An important factor to mention is that this is an association. There are lots of things that go into a diagnosis.

When we talk about "energy balance", that's one thing we can be in charge of, where we can move a little bit more on days we feel well. Or

we can start to engage in a slow and progressive exercise program. That's a very important target for us, and I encourage our patients, even when they're going through treatment, if you feel good on a given day, go ahead and take a walk or make sure you're staying active. If you don't feel very well that day, then just take it easy.

As you continue to gain energy and as you continue to move out of your acute treatment, it's very important to continue exercising on a regular basis. We also know that resistance training can be helpful, and that using some light weights is helpful. But it's also very important to have instruction because there can obviously be some risks depending on some of the other issues that we talked about today, like having lymph nodes removed. This is, once again, a very important discussion to have with your provider.

It's also important to maintain a healthy diet and that includes eating as many fruits and vegetables and whole grains as we can. Also, looking at some of the other dietary requirements for maintaining a healthy weight, which may include calorie restriction to help us lose weight. Achieving a healthy weight may include our active role of losing weight.

One of the things that Jennifer Thompson will talk with you about in a few minutes are some of the resources that you'll have available which include some exercise DVDs as well as a kosher or a Back In The Swing cookbook. These are great resources to help you understand how to achieve that healthy weight, and how to keep active and eat things that not only taste good, but also have some helpful benefits as well.

The last part of healthy living has to do with supplementation. We do need to be careful with supplementation. These are medicines, just like some of the other pills that we take, so make sure that you're fully disclosing what medicines and supplements you take with your provider to make sure there's no contraindications or interference between the supplements, and some of the other medications that have been prescribed.

With that, I'm going to transition back to Rochelle, who will introduce Lillie.

Rochelle S: Thank you, Dr. Klemp. We'll all have an opportunity to ask Dr. Klemp questions during the question and answer period at the end of the teleconference, but first allow me to introduce our next speaker, Lillie Shockney. Lillie Shockney is a University-Distinguished Service Associate Professor of Breast Cancer and the Administrative Director of the Johns Hopkins Breast Center since 1997.

A two-time breast cancer survivor, she's a published author of more than 13 books, a nationally recognized public speaker on the subject of breast cancer, and the editor-in-chief of Journal of Oncology Navigation and Survivorship. Tonight, Lillie Shockney will provide an overview of what survivorship care plans are, the different types of care plans available to you, how you can complete them with your medical team, and how they can help ease anxiety as you navigate your breast cancer journey. Welcome Lillie Shockney and thank you for being with us.

III. Survivorship Care Plans

Lillie: Thanks very much for having me and I am thrilled to know that there are so many people that are listening in this evening. I want to start off by saying that I know that many of you who are tuned in with us this evening are perhaps just winding down your acute treatment, surgery, chemotherapy, and radiation. Others of you may have completed these phases of acute treatment some time ago, and are in short-term or perhaps even long-term survivorship care. There are individuals who are going to always be receiving some degree of treatment and are living with their cancer, being stage IV metastatic breast cancer.

I want to talk a little bit first about treatment summaries and survivorship care plans. One of the catalysts, interestingly enough, for the development of and need for these actually came from two different venues. One was the recognition that there is a growing shortage of oncology specialists in the United States, while there is a dramatically increasing incidence of individuals diagnosed with cancer, and subsequently surviving their cancer. 24% of individuals diagnosed today who are survivors, like myself and all of you, are in fact breast cancer survivors.

As a result of this, it's projected by the year 2020 that we will have a 41% to 48% deficit of oncologists in the United States. That's a very big number to have to deal with, and as a result of that, oncologists, whether they are surgical oncologists, medical oncologists, or radiation oncologists will not be able to follow cancer patients and specifically breast cancer patients and survivors long-term. The necessity is for us to engage very much in understanding what our treatment is, participate in the decision-making about the treatments that we are receiving, and have a nicely laid-out treatment summary, as well as a survivorship care plan that really does serve as a guide as to what needs to happen going forward. What type of surveillance will we need to have done? Who will be responsible for doing that?

I really emphasize today to survivors, we as survivors have to step up to the plate and make sure we are engaging in self-management on behalf of ourselves. Primary care physicians have been experiencing a shortage for longer than I can even count.

I recently read a research article that made me feel very sad. Tens of thousands of physicians participated in it. It was a time-motion study performed on primary care physicians, demonstrating that every 16 minutes is the length of time that we have with a primary care physician, and that during that time, the amount of time that is being spent on the reason why we went to that doctor is 14 minutes for cold, flu, back ache, whatever it is that we may have. They reserve then one minute to talk about other co-morbid conditions we may have of asthma or high blood pressure, etc. That leaves one minute, and I mean that literally, one minute left for cancer survivorship. You can imagine that if we don't take the bull by the horns and make sure that we are having our needs addressed and assuming some responsibility and also, addressing those needs, then something's going to fall through the cracks.

At the same time all of this was happening, Hurricane Katrina hit. The tens of thousands of individuals that lived in New Orleans and were cancer survivors or currently, cancer patients undergoing active treatment, there were no medical records that, in essence, survived. Patients didn't know what treatments they were receiving. For breast cancers patients, I spoke to one of them and they said, "I'm getting a red medicine in my vein. I think I get it every two weeks, but I can't remember. I think I've had two cycles, but maybe, it's been three." A natural disaster can also force us to take a look at how are we record-keeping and how are we engaging patients in making sure that they do understand what they're treatment has been, and what is needed as we go forward for survivorship.

From a treatment summary perspective, first, it's important that we know who your treatment team has been to date and how do you go about reaching them. Often times, physicians will hand out their business cards, but if you call the number on there, you may find out that they don't take patient calls, and that there's someone else, perhaps a nurse practitioner, who was the one that handles that on their behalf and you weren't informed about that.

A summary of your genetics evaluation, including testing results and your family's history of breast cancer and ovarian cancer, as well as other types of cancers, whether that be melanoma or colorectal, pancreatic, etc. Keep in mind that as family members are newly diagnosed in the future and there will be some that this will happen to, that portion of the summary needs to be updated.

It's something that I've been talking to PCPs about over the last two years, as a gentle reminder to always, whenever they're seeing a cancer survivor to ask that question, "Have any of your family members been diagnosed with cancer since I last saw you?" We may not have thought about a genetic link, initially. Over time, as more individuals potentially get diagnosed within a family, we then may want to steer people to genetic counseling and, potentially, subsequent testing.

Who will want to have recorded the details of your treatment? What surgeries have been performed, if lymph nodes were removed and then how many were taken out? The details of your pathology results, including the type of breast cancer that you had, the prognostic factors of that pathology report and specifically, about those tumors cells, the pre-chemotherapy test results that were done, like an echocardiogram, for example. Details about chemotherapy, if it was part of your treatment, and if you participated in a clinical trial, and if so, which one was it?

What side effects did you experience during your treatment and what ones are continuing to linger now, if you've perhaps completed your chemotherapy, radiation, and other treatments? Also, what possible side effects in the form of long-term side effects should you know about that may crop up in the future and could appear, perhaps, a decade from now?

The same applies to radiation therapy and hormonal therapy. At any point before treatment, when treatment stops or is put on hold due to the severity of side effects or perhaps low blood counts, all of that should be noted. List all of the medications that you take, including over-the-counter meds and any herbs or vitamins or other substances that you're taking, and that includes anything topically.

All of the above information that I have just referenced is important so that you and others are not relying on memory 10 to 20 years from now regarding what your treatment entailed. We all think that because we've been through it and remember it so well, that we will always remember it and it's like giving birth to a baby. You remember the really hard labor in retrospect and just have a vague image of it.

It's important to also provide clues to certain symptoms that you develop later which may be related to your treatment. It is also very important if you were, heaven forbid, to develop recurrence as the same treatments you have had in the form of medicines and radiation may not be able to be given to you again.

Follow-up recommendations need to be customized to you. Though there are some guiding principles, that doesn't mean that all breast cancer survivors have the same follow-up instructions, by any means. The only two cancer diagnoses at the current time that do have definitive surveillance follow-up guidelines are breast cancer and colorectal cancer. The NCCN (National Comprehensive Cancer Network) is busy working on the developments of others for other types of cancer, but currently, it is only breast cancer and colorectal that's in print.

In looking at how things might vary from one survivor to another, if you had had bilateral mastectomies, you would no longer need to have, for example, mammograms performed, whereas if you had a lumpectomy, you would likely be getting a mammogram on the affected breast twice a year for one to two years, then resuming annually thereafter. Your specific situation may warrant an MRI at specific intervals. For those on certain hormonal therapy drugs, a bone density test would need to be performed and documented, and specified at what intervals. Pelvic exams and their frequency also need to be clearly stated and followed.

One of the nice tools contained in the care plan Sharsheret provides includes the ability "to check in with yourself" and I thought that was a very clever way to document this and to perform a self-assessment. Having information regarding how you can help to manage long-term side effects, deal with fear of recurrence and I'm 20 1/2 years out, and it's still totally not left my brain, when I get an ache or pain or a cold that won't go away, that's certainly what's on my mind. Also, decision-making in the future about genetic counseling and testing, understanding your patient's rights, too, are all important to know about.

We all know that though breast cancer happens to you, it really affects everyone who lives with you, and certainly, everyone who loves you. Receiving guidance regarding how to communicate to your children, if appropriate, about their genetic risk. Even deciding how much information you want to share with others needs to be discussed. You may have some specific assurance regarding your children, too, such as your comfort level on your daughter going on the birth control pill in the future.

There is also a section that focuses on health and well-being concerns. Some are associated with lifestyle behaviors that you may want to consider improving such as weight management, smoking cessation, exercise, understanding and managing fatigue, coping with anxiety issues, are all important to address. There may be also some treatments that have resulted in your inability to fulfill some of your life goals. Becoming infertile, for example, can be a side effect of chemotherapy and or hormonal therapy.

For those who are still in treatment, knowing what questions to ask related to the opportunity for fertility preservation. Are you eligible to adopt a child in the future? What is the risk of passing a breast cancer gene on to your children? For those who are single, deciphering when is the right time to bring up your medical history with someone that you're newly dating or forming a relationship with? For those in a relationship, when and how to feel comfortable resuming sexual activity? How can you manage menopausal symptoms and their impact on intimacy?

Last, but not least, is a section on psycho-social and spiritual concerns. There can be a tendency among those you love, as well as those you work with, to not think and feel the same way that your treatment is considered when you hear the word that your treatment is "done." That word "done" as we know is a very relative word in this equation. Others may expect you to go back to your old self, whatever that was.

You have been through a life-altering experience, and you need to work within yourself to determine and understand what does surviving all of this mean to you? How to acclimate yourself to your new body image? You may be mourning the loss of your breasts or you may have taken this experience and decided to find all of the pearls that come from it.

Whatever your experience and decision is, it's very personal and you may want to speak with your Rabbi, or your spouse, or another person that you feel close to. I have heard people say that the patient has to "adjusting to her new normal" or perhaps "find her new normal," as if it is missing. I prefer to recommend to patients, and I say this at the time that I first meet them, which is usually within 48 hours of them having heard those words "you have breast cancer", I tell them I want to work with you to help you *design* your new normal. We're going to *create* your new normal. You don't have to settle for something and you don't have to accept something and you certainly don't have to go and hunt for your new normal.

Let's see what we can do to prevent side effects or to diminish them. Let's keep you on track for your life goals whenever possible, including that fertility preservation, my being proactive prior to us beginning any treatments. It's not too late in many cases to still implement those life goals at the finality of treatment, but you need to bring them up and make your oncology team aware of them.

Who should have copies of these documents? Your oncology team members, certainly your gynecologist, your PCP (primary care physician), and of course, you. I've also wondered about whether or not will the time come that we should be providing a copy of these also to our health

insurance carriers? These are the people and the companies that we expect to be paying for the surveillance tests that are going to be done, the frequency with which we're going to be examined, and by whom. I think at some point in time we need to bring them into the fold rather than just assuming that they are automatically going to provide pre-authorization for the things that your oncology team has deemed important.

There's also a need to be clear about the delineation and responsibilities as to "who is to do what" so we don't duplicate a test or we don't omit a test. For example, your gynecologist may be assuming that your PCP is ordering your mammogram or your bone density, when the PCP is assuming the opposite. This could result in having two of these tests done, or none of these tests done, or a mammogram done and three months later, another mammogram done.

Additional information that is not part of the survivorship care plan, but should be considered for inclusion, are wellness and other cancer screenings, such as colonoscopy. When to get your flu shot? How about a shingles vaccine? Your dental visits, as well as what your results were from your scans that may have been done in the past if a stage workup was for some reason needed to be performed?

This type of summary enables you to move forward with short and long-term follow-up care. For those of you who do not have such a document, it is never too late to create your own. You can request copies of your medical records from the various oncology providers who took care of you. (If you have trouble translating the information contained within it, then you can call the Sharsheret hotline at 866.474.2774 and get guidance.) You might also want to talk with a nurse practitioner who has been involved with your care or the nurse navigator who has been involved with coordination of your care.

It is of particular importance for me to mention that cancer centers that are accredited as NCI-designated community cancer centers, teaching cancer centers, or comprehensive cancer centers, are required to be providing these types of documents as part of survivorship care. These standards were developed and implemented beginning in 2012 which now has gone by. By the year 2015, there is an expectation that all cancer survivors, no matter what type of cancer that they have, will have in their hand this type of document. Ideally, a treatment summary would grow concurrently, as the treatment is taking place.

This is of particular need, as I mentioned, because of the shortage that we are facing of oncologists. I caution you in saying that you may have an

oncologist that reassures you and says, "My dear, I will be seeing you forever, don't worry about any of this." As his conveyor belt gets speeded up, and we try to put ten pounds of salt in his five pound bag, what will happen is that he will today be seeing five newly diagnosed and following 20 follow-up patients. A year from now though, he may be seeing eight newly diagnosed patients, and he does not have time to still see those 20 follow-ups. Those follow-ups are where you are.

There are currently 14 million cancer survivors of which 24% are us, breast cancer survivors. That number's going to grow to 22 million by the year 2020 and we are a large, large, large group of those individuals. Take pride in being a survivor. For those that are dealing with metastatic disease, I want to tell you a mantra Rosemary, one of our survivor volunteers, who passed away a year and a half ago, has always asked me to mention which is women who are surviving with their disease and living with stage IV breast cancer have a choice. They can be dying each day or they can be living each day with their disease.

I feel confident that all of you out there are making strides in living with your breast cancer. Thank you.

Rochelle: Thank you so much Ms. Shockney. Chock full of information and I know plenty of us will have questions for you during the question and answer period. First, I wanted to introduce Jennifer Thompson, who is the Survivorship Program Supervisor at Sharsheret, who will tell us more about Sharsheret's new Thriving Again program and the ways in which we can all participate. She along with Danna Averbook of our staff is responsible for putting together tonight's teleconference so I want to thank them both while I have them on the line.

IV. Thriving Again

Jennifer T: Thank you, Rochelle. Tonight we have heard a lot about what it means to be a breast cancer survivor. We have explored some of the issues that breast cancer survivors face, such as diet and exercise. We have learned a lot about what survivorship care plans are and how they can be helpful to you, as you navigate your breast cancer journey.

Before we start taking questions, I wanted to tell you a little bit about the exciting new program that Sharsheret has to offer that addresses these and many more of the concerns that you may have. Sharsheret's

survivorship program, Thriving Again, offers breast cancer survivors support navigating their entire breast cancer journey. Whether you are newly diagnosed, years beyond treatment, or living with metastatic disease, there is something for you.

When you connect with Sharsheret, a member of our clinical team will speak with you about where you are in your breast cancer journey and what your unique needs are. Our team can connect you with a certified genetic counselor that offers both individual and family counseling sessions, and a peer supporter, who can speak with you about many of your survivorship needs.

Once you have completed treatment, you will also receive your tailored survivorship kit that we've spoken about briefly this evening. The kit includes information on many of the topics that we have heard about tonight, and you'll also be able to choose from a number of other resources that might be important to you, such as family planning, parenting, using the mikvah, and preparing for Jewish holidays as a survivor. Your kit also includes a customized care plan and guidance from our clinical staff on how you can complete it with your health care team.

Finally, you will choose a healthy living cookbook for us to include, and select one of our five fitness DVDs, all of which can help you live the healthiest lifestyle possible. Sometimes, it's helpful to know that there is someone you can call with your questions, whenever you have them, and that's what Thriving Again offers. It offers the tailored support and help navigating your unique journey through breast cancer. It's pretty easy to order a kit. If you haven't ordered one already, the link will be provided to you in the e-mail that you receive tomorrow from Sharsheret. If you have any questions about the kit, or trouble ordering, you can always give our office a call at 866.474.2774.

With that, I'm going to open the floor for questions and answers this evening. You can ask questions of all of our speakers, and we will try to get to as many of the questions as possible. We have over 80 participants on the call this evening though, so it might be a little challenging. The only thing I ask is if you could please keep your questions general and broad, so that all of our participants can benefit from the discussion.

V. Questions and Answers

Jennifer T: We're going to jump right into the questions. The first one is for Rochelle. As a seasoned cancer survivor of 12 years, do you have any tips for new survivors?

Rochelle S: Now that Lillie Shockney has spoken, I don't feel so seasoned anymore. She's the real survivorship expert. If I could share one of the nuggets that I've taken away from my cancer journey, I would say it would be this: I think as a survivor, one of the most important things for me has been learning to keep my mind as healthy as my body often feels.

I feel okay so many of the days, and I think it's important, for me, to keep my head in the game and recognize that although there might be times that I feel fearful and anxious, I am okay and learning to live comfortably despite cancer. I think the challenge that many of us face is when we let our heads get ahead of our body and then take us to that bad place.

I think because survivorship is such an important topic now, there are many groups and organizations like Sharsheret that are offering continued support for survivors. There's a community for us. There is a place to reach out when we go to that bad place. Making sure that we keep our heads as healthy as our body feels has been a really important factor in my own survivorship journey. I'd be curious to hear what Lillie has to say about that.

Lillie S: Very good point. I think those are incredibly wise words. I have a phrase that I keep on my bulletin board at home, as well as at work. It says, "Worrying does not empty tomorrow of its troubles; it empties today of its strength." I always have to do an "Okay, how worried should I be about this symptom or this whatever that is that's toying with my brain?"

I've come to learn that if we allow cancer to keep creeping back into our head too often, then what we've actually done is given cancer more time than it deserves. I only want cancer to be given the time that we need to give it to get rid of it, or keep it in control. I don't want it to have any more of my time or your time, not our family time or social time or personal time or work time, none of it.

I always wanted to remind myself and I do, "I am in charge. The cancer is not. Am I doing the right things in order to stay healthy? Yes, I think I am." If I slip then I remind myself and say, "Okay that cheesecake was maybe not a good idea or the second piece wasn't a good idea."

Remaining informed. We really do empower ourselves by having information. That's something that you're all doing this evening so staying abreast, pun intended, of what is the latest research that's being released that furthered the agenda of understanding better treatments, understanding a clear way of diagnosing, as well as what to expect going forward.

As more research studies are completed, I always like to follow up and see now that we've got ten years of data, what are the side effects that we didn't know five years ago, but that we do know now? How can we make sure that the right people are being alerted about that if they were on that particular drug or received that particular treatment? Hold on to your power women. We are in charge.

Jennifer T: Fantastic, thank you so much. The next question is for Dr. Klemp. The question is about Herceptin. How long is it recommended that individuals be on it or can you offer a little insight into that?

Dr. Klemp: Yes, Herceptin is a targeted therapy that patients who have a certain type of gene are given. It's a gene that we all have, but it's whether or not it's turned on. One thing that I like to do is that I compare how cancer works to a car. If you think about breast cancer, we have the gas tank and that could be estrogen. That can fuel how our cancer grows. The HER2 gene is what turns it on so it's your ignition. The drug Herceptin affects that and turns that back off or quiets that gene. Herceptin is given to patients that are HER2-positive or that gene is turned on and it improves survival locations by as much as 50%. It's truly a targeted therapy that has made a huge difference in breast cancer survivors.

It is generally given for up to a year and then for women with a more chronic or advanced disease, it can be given long-term. The challenge with Herceptin - it has some side effects to the heart. If you're receiving that type of treatment, Lillie mentioned something called "an ejection fraction" and that's a test that's done to look at how efficient that muscle of the heart is that pumps, because Herceptin, just like other drugs like anthracyclines and some of our other types of therapies, can be a little bit harsh on the heart. It's important to make sure that you have echocardiograms or MUGA scans before you start treatment and that's what looks at what's called the "ejection fraction." Then they're going to put you on a regimen going forward to continue to monitor that.

A lot of my research is in cardiac risk in cancer and one thing I'll say, which I think is truly amazing, not about Herceptin which is also amazing, but there was an article out last summer which talked about the fact that long-term breast cancer survivors are more likely to die of cardiovascular disease now than their breast cancer. This is one reason why we have to look at the bigger picture of our patients, as we provide those personalized recommendations going forward.

I hope that answers your question about Herceptin and it is definitely something you want to talk with your provider about to make sure you

understand what type of regimen you're on, how long you'll be on that, and then to talk with them about those side effects.

Jennifer T: Thank you so much. I have a follow-up question on treatments and medications. Rochelle, what are the best ways to stay informed on current research and studies on specific medications or treatments that women might be on? Where should they be going to find that information?

Rochelle S: One way to stay on top of emerging research is to stay connected to organizations that offer teleconferences like this one. There are a host of breast cancer organizations that can keep you apprised of emerging research. I think staying connected to the breast cancer community, even though our inclination might be to "get away from cancer," it's important to keep at least a toe in the door, if not the entire foot.

We have a second way to keep apprised - we all have follow up appointments and follow-up scans. Another great way to stay on top of things is to ask your doctor or nurse practitioner at every appointment, "Is there anything new that I need to know?"

Third, for those of you who don't know, there is a big breast cancer symposium called the San Antonio Breast Cancer Symposium that takes place every December in San Antonio, Texas. The news, local media and national media, always covers research that emerges from San Antonio. If you do nothing more than turn your antenna on to the news during the week in December that the Breast Cancer Symposium is happening, you'll get a good synopsis of some of the key studies that are emerging. Those are three quick ways to stay on top of things.

Lillie S: This is Lillie Shockney. Let me mention one other ways which is if you go to the Johns Hopkins Breast Center website, which is Hopkinsbreastcenter.org, on the homepage down the right-hand side you'll see a little statue of Artemis, the Greek goddess, supposed to be the protector of all women, who had 100 breasts.

If you click on her, Artemis is the name of our electronic medical journal. I publish on there the first of every month 25 to 30 abstracts translated into layman's terms that are the result of combing through all the medical peer-review journals that have published evidence-based research associated with breast cancer and breast health. That gives you a snapshot every month, if you want to take a look there.

I think one of the things that we can torment ourselves with is a new drug may come out and you'll say, "I want to get that drug now." The drug is

appropriate to give during acute treatment, and let's say your two years out and you are doing fine, but you say, "That drug showed a higher survival rate than the drug that I got so I want that drug now." You could do this forever. Hopefully, we will always have new treatments coming out and we have to realize that we made decisions at the time of our diagnosis and treatment based on the information available at that moment.

I'd also like to mention that there can be a tendency, particularly those as they transition from their oncology specialist team back to their PCP and GYN, to want to ask for a full-staging workup. Say, "I don't think I trust this doctor to be able to take care of me as well as my oncologist was. I want a PETt-CT, and a bone scan, and a chest X-ray, and a CAT scan, everything."

It really isn't appropriate to do that. There is very specific criteria as to when a staging workup of that nature should be done. If you were to look at my scans that I had done now, long ago and 20 years ago staging workups were commonplace at the time of diagnosis, and for some time after that. You would say, "When did she die?" Because I've had 19 bone fractures in my lifetime and they all leave a little hot spot on my bone scan.

I have various things in my lungs from growing up on a farm and all of them, at one point in time, had to be chased down in the form of biopsies, which was very unpleasant. Bone biopsies are no fun, lung biopsies aren't much fun either. So relying on symptoms instead is what we are to be doing for ourselves and the doctors taking care of us should be doing.

If you have a new abnormal symptom of, let's say, right hip pain that is new, it's lingering now and it's consistent or three weeks, it's not related to you picking up furniture or laying new carpet or something else that you can account for it, that is appropriate to bring to the attention of the provider that's going to be managing you from a survivorship care perspective. That individual should be talking with your oncologist to determine is this the right time to do a scan or do we already know the cause of this and how do we remedy it? Thank you.

Dr. Klemp: If I could just chime in. This is Jennifer Klemp, real quick. I'm a very evidence-based person, as we just talked about the importance of having information and education. There is a very well-respected resource for you, if you've never gone there, it's through the National Comprehensive Cancer Network or NCCN. If you go to NCCN.org they actually have a patient guideline for breast cancer. Just like Lillie was talking about, how it's important to note that things change over time and we have standard guidelines, this is expert and evidence-based recommendations that are

put together that many clinicians across the country follow, as well as this is how insurance companies will reimburse care. That's a nice resource for you guys to take a look at, too. Thank you.

Jennifer T: Thank you all so much for that input. If anyone on the call this evening has questions about those resources or any of the other websites, you can always contact Sharsheret and we'll be happy to give you those websites again. The next question is for Lillie. You've talked about it briefly, but could you expand more on what is normal follow-up screening? Especially, if your medical team isn't proactive and speaking about it with you, what can you expect or what questions should you be asking?

Lillie S: I'm a believer in looking at things by stage and prognostic factors. I don't think that one size fits all. If an individual's had, for example, a lumpectomy, then we would anticipate that she would have a follow-up mammogram on the lumpectomy side twice a year, so every six months times two years so that's four in a row of those, while still maintaining an annual mammogram on the contra lateral side on the opposite breast.

Once you've hit two years of having "normal" mammograms so that they weren't seeing something that then subsequently resulted in a biopsy, then women can go on to have annual mammograms again. If the breast imaging radiologist (please note I did say "breast imaging" radiologist, I didn't just say radiologist) has determined based on the density of the breast tissue that it is difficult to find the "polar bear in that snowstorm" of that breast tissue, then it is his or her call as to whether or not a breast MRI should also be part of surveillance, and with what frequency that should occur. Some will recommend doing an MRI and alternating that six months later with the traditional digital mammography.

Also, for those who have had mastectomy, whether that be with or without reconstruction, there is no standard that says to get a mammogram of the reconstructed side. We don't take mammograms of an implant lying on the table. We also don't take a mammogram of women's abdominal fat before we move it up or their heiny fat before we bring it around. What is more accurate in identifying local recurrence is actually a clinical breast exam. That is the best way to see if there is local recurrence or not.

I recommend asking your breast surgeon, "How much tissue did you or did you not leave behind?" if you've had skin sparing mastectomy." Some surgeons leave quite a bit of tissue behind so it's actually like having a giant lumpectomy instead of a true skin sparing mastectomy. If that surgeon is the type that leaves, let's say, one to two centimeters of breast tissue behind, then you're going to be at higher risk for a local recurrence

than someone who does create relatively thin flaps, still maintaining good blood circulation.

For those who are on hormone therapy, they should expect to be seen every six months by an oncology provider. That does not necessarily mean the medical oncologist. It could mean the medical oncologist this time, six months later the medical oncology nurse practitioner, who's also been involved in your acute treatment, and ongoing treatment, and then back to the medical oncologist again.

For radiation therapy, usually radiation oncologists will cut the patient loose at the two-year mark and some cases even sooner than that. It's unusual to see a radiation oncologist follow a patient much beyond the two-year mark today. Where the challenges come in to be are those individuals who are at higher risk and how closely do they need to be followed and who should be following them.

For those individuals, for example, who do carry a breast cancer gene and have not done aggressive, proactive surgical intervention of bilateral mastectomies, bilateral salpingectomy, then those individuals should be followed in a high risk clinic because they are high risk for breast cancer or ovarian cancer, returning far more so than someone who does not have a breast cancer gene.

Where I think the patients and where we need to do a better job is in looking at measuring the risk of local recurrence and risk of distant recurrence and stratifying our long-term follow-up based on that. Someone with stage III-C breast cancer, has a very high risk of local recurrence and distant recurrence in the form of metastatic disease. We hold on to those patients for seven to eight years because of so many of them are going to have one or the other from a recurrence perspective.

If someone is a stage II breast cancer survivor, has very favorable prognostic factors of hormone receptor positive, HER2-negative, then we are usually comfortable in transitioning that patient, usually between the two and three year marks. You see stratifying based on risk of that recurrence. We as oncology providers, I believe are responsible to inform the patient the first time we meet her, "This is what to expect across the trajectory of your care, that we're forming a relationship here today, here's the members of the team that are going to be involved in taking care of you". You're going to meet some additional team members once we know a little bit more about the pathology of your tumor and it will more than likely be at this transition point for this transition point when we will re-engage your PCP and GYN." I've tried to drum up enthusiasm among GYNs and PCPs to never disconnect from the patient.

Jennifer T: Thank you. Several callers have called in actually about Tamoxifen, and I was wondering if Dr. Klemp could address that, as well the newest Tamoxifen studies that have come out.

Dr. Klemp: Rochelle mentioned the San Antonio Breast Cancer Symposium and I was down there in December 2012, and the highlights in regard to Tamoxifen, which is generally given to endocrine-positive so that estrogen receptor positive breast cancer and especially, if the woman is pre-menopausal at the time of diagnosis, they found that giving the Tamoxifen therapy for 10 years was superior than our traditional five years.

It was once again all over the news, and it does make an impact because prior to, we discontinued at about the five year mark. Having said that, if you look across the country, providers keep patients on anti-hormonal therapies for all different reasons. I think the term that is so important to think about, and it's a term that Lillie just brought up, is the word "risk stratification."

Providers may choose not to leave patients on longer because maybe the risk is lower or maybe the patient is not tolerating the therapy as well. It's important to know that data tells us how to achieve ultimate outcomes in a certain population. Usually, that population is a very pure, if you will, population of patients who don't necessarily have some of the co-morbidities or other health issues that some of our patients have. It's not always "apples to apples." It's often "apples to pears," or "apples to oranges." It's very important not to take data and always interpret it to ourselves until we can discuss that with our provider and make sure that we're the best fit for that.

For many of you, as women transition through menopause, another transition point, or if they were diagnosed as a post-menopausal woman, we use therapies called aromatase inhibitors and there's several different types of those. Those are very important drugs and have very good rates of managing disease and have good outcomes. They do have their own series of side effects including some bone health issues.

Once again, it's important to understand why do we give these therapies potentially, for five years or longer? What does the data tell us? Do we fit into that data, so what should our plan or our personal plan be? I'll stop there and see if I answered that question appropriately.

Jennifer T: I think that's great information and asking our providers is always a great starting point. Thank you so much. The next question is actually for you as well. Piggybacking on the lifestyle changes that you had discussed

earlier this evening, there are a couple of questions about other things that survivors can do to make lifestyle changes like smoking and alcohol cessation. If you could speak a little bit about what impact they have on recurrence and if there are any recommendations for limiting smoking and alcohol drinking, that would be great.

Dr. Klemp: Smoking is a carcinogen or it is a known cancer-related agent. Smoking cessation is something that if it hasn't been discussed with you and you are an active smoker, even a light smoker, it's very important to engage in an active smoking cessation program.

There are some associations with breast cancer as well, and a lot of studies out there. Once again depending on what you look at and how you slice it, you may find your answer is that there's not an association, but the reality is, it's very important to target a discontinuation of smoking. It is a very hard task and so it's one of those things like dieting, whether you try, try, try again and you keep at it because eventually, it does have a lot more pay off by committing to that, but very hard to do.

Alcohol has some interesting data. A lot of it has to do with following populations for long periods of time and especially in nurses in the state of California. In San Antonio, actually two years ago, they had a very nice study by Dr. Leslie Bernstein, where she highlighted how much alcohol can we really drink and should we just eliminate it altogether? There's, once again, lots of different stories out there, but the reality is that we try to justify "well maybe there's some heart health benefits, should we drink the red wines?"

The average consumption per day was about four ounces. If you measure out four ounces, it's really small and I think we have such a warped perception of portions that that's a very tiny amount. If you looked at amount over that on a daily basis, that led to an increased risk for breast cancer. It's important to think about, "I don't drink every day. I only have, maybe two glasses of wine with dinner on Friday." There isn't data on two glasses of wine on a Friday. I think the hard part is that we do encourage very limited intake of alcohol and trying to do that in moderation.

I think that the moral of the story is moderation is a huge part of this. It's finding your balance and that's why I think "energy balance" is such a nice term because it helps us find our groove and allows us to find that balance, but it's also important to understand that there's always a cost-benefit to a lot of things. Sometimes, we don't have data to support our decision, but we do need to be moderate with our behaviors.

Jennifer T: Thank you so much. I think that it's also a great tie-in to the Sharsheret Thriving Again program. If you want more information on smoking cessation or alcohol, you can request that information in your tailored survivorship kit. We'll be happy to provide that to the women who are interested in that information. We are nearing the end of our teleconference this evening. The last question is actually going to go to both you, Dr. Klemp and Lillie. If you could each offer just one thing that you think breast cancer survivors need to know, the one takeaway that you would offer them this evening, that would be fantastic and we can start with you Lillie, and then we'll go to Dr. Klemp, as well.

Lillie S: I'm a believer that no matter how wonderful we thought our life was or wasn't before we were diagnosed, we should use this experience to the good. Create a life for ourselves that truly is a wonderful life. There can be times that you may say, "I don't say I'm going to do that because I continue to deal with all these side effects." I want you to seek the pearls. Those of you that may know me, I very purposefully set out to do that, feeling that this was perhaps "why this happened to me." I still feel that way 20 years later.

Jennifer T: Thank you and Dr. Klemp?

Dr. Klemp: I think building on what Lillie just mentioned, I think that it's our responsibility, regardless of what our situation is, to be empowered. We do that with education and by asking questions, and being part of that process. The other part of that, which I think is very important for us to think about, is that we have to have realistic expectations of what we're doing, what our outcomes will be, and what's realistic in regards to the medical community and the treatments that we have access to.

We talked about some of the great programming that we have in our community. We have breast cancer survivorship centers and high risk programs, but not all communities have access to those resources. I think it's very important to understand what are the ideals and what can we hope for you? But that may not be possible so sometimes you may know more or ask questions of your providers that they may not be the greatest at answering. It's important to have high expectations, but also be okay with what sometimes is available, and practical, and realistic for the community. It doesn't mean there's not national and other resources such as Sharsheret and others out there that you shouldn't seek that information from. Be your own advocate.

Jennifer: Thank you and Rochelle?

VI. Conclusion

Rochelle: I will answer last and then wrap things up. I think those are all absolutely wonderful takeaways. I think, for me, the thing that I would suggest that people need to know about breast cancer survivorship is to understand what's just happened. I think we get out of treatment and we probably, for the first time in a long time, have an opportunity to understand what just happened to us.

During the course of treatment, we're really busy and active and making decisions and learning a lot and the learning curve is steep. We finally, during the survivorship period, have an opportunity to slow down a bit and take stock of what's just happened. I think the Survivorship Care Plan that takes us back in time and helps us record what just happened to us is a critical beginning step in living a full life as a survivor.

I'm always surprised at how many details I missed in the course of my own treatment, and how important some of those details become later on. I would say taking stock of what happened is probably a really important first step in becoming a survivor.

With that, I want to thank everyone for anticipating tonight. We had so much information from Dr. Klemp and Lillie Shockney. Almost hard to absorb it all, but the good news is we'll have a transcript posted online at www.sharsheret.org, and that will be available for you in case you want to look back and read a little bit more about some of the things you may have missed, or share it with a friend or your health care professionals.

We will also send you an e-mail about completing a survey and we'd really appreciate it if you took the time to do that. Your feedback is really helpful for us in building our programming. I think tonight, more than anything, we all recognize that survivorship is challenging and can bring with it just as many questions as the breast cancer diagnosis itself can. There's support out there in navigating it and understanding it. You can receive more information, resources, support, and your tailored survivorship kit by contacting Sharsheret. Find us on Facebook and on our website, www.sharsheret.org. Call us toll-free at 866.474.2774. We'd love to connect with all of you. Thank you, again, to our speakers and wishing you all continued blessings on this journey and every journey. Have a good night.

VII. Speakers' Biographies

Rochelle Shoretz, Esq., Founder and Executive Director, is a two-time breast cancer survivor who founded Sharsheret after her own diagnosis at age 28. Rochelle served as a law clerk in 1999 to U.S. Supreme Court Justice Ruth Bader Ginsburg. A member of the Federal Advisory Committee on Breast Cancer in Young Women, Rochelle speaks to audiences across the country and serves as a resource for major media on issues related to breast cancer in young women and Jewish families.

Dr. Jennifer Klemp, is an Assistant Professor, Cancer and Genetic Counselor, and the Director of Cancer Survivorship, at the University of Kansas Cancer Center. She was recently asked to serve on the National Cancer Survivorship Resource Center's Quality of Life: Survivorship Programs & Navigation Workgroup. She has worked in the field of breast cancer prevention and survivorship since 1996 and has a clinical research interest in understanding breast cancer risk, cancer genetics, quality of life, and lifestyle modification. She is the Founder and CEO of Cancer Survivorship Training, Inc., an eLearning company supporting healthcare professionals. She earned her Master's in Public Health at the University of Kansas Medical Center, a Master's in Clinical Psychology from the University of Kansas, and completed her doctorate in Clinical Psychology- Health Specialty, from the University of Kansas. Her dissertation work was entitled "Evaluating the effects of chemotherapy on cognitive function and quality of life in pre-menopausal women with breast cancer". Jennifer completed her Internship at Rush University Medical Center, Chicago, IL, in the Department of Behavioral Sciences. She has published and presented work with a focus on cancer genetics, alternatives to screening in high-risk women, compliance with a mobile mammography and educational intervention, shared decision-making regarding options to manage breast cancer risk, and the development cancer survivorship programming.

Lillie Shockney, RN.,BS., MAS, has been the administrative director of the Johns Hopkins Breast Center since 1997. A two-time breast cancer survivor, Lillie has worked tirelessly to improve the care of breast cancer patients around the world. She is a registered nurse with a Bachelor of Science degree in health care administration from Saint Joseph's College and a Masters in Administrative Science from the Johns Hopkins University. She has worked at Johns Hopkins since 1983. She is responsible for the quality of care programs; patient education programs; the survivor volunteer team; community outreach at a local, regional and national level; the Web site and patient advocacy. She is also certified as a breast imaging and breast cancer patient navigator.

Lillie is a published author and nationally recognized public speaker on the subject of breast cancer. She has written 13 books and more than 250 articles on this subject. She serves on the medical advisory board of several national breast cancer organizations and is the co-founder and vice president of a national non-profit organization called Mothers Supporting Daughters with Breast Cancer.

Lillie is also editor-in-chief of a new peer-reviewed medicine journal called Journal of Oncology Navigation and Survivorship, which launched in Spring 2011. She also serves on the Leadership Council of the Academy of Oncology Nurse Navigators (AONN), a national organization that provides a network for all professionals involved and interested in patient navigation and survivorship care services to better manage the complexities of the cancer care treatment continuum for their patients. She is also the recipient of numerous professional and community service awards.

Jennifer Thompson, MSW, is the Survivorship Program Supervisor at Sharsheret. Jennifer is a graduate of Columbia University School of Social work and has vast experience in cancer advocacy, public policy, analysis, and legislative initiatives. Prior to joining Sharsheret, Jennifer served as a Senior Advisor to Mayor Michael Bloomberg and Director of Advocacy for the American Lung Association. Jennifer spearheads and oversees the development of “Thriving Again”, Sharsheret’s new culturally-relevant support and education program for young Jewish breast cancer survivors and their families.

VIII. About Sharsheret

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

Since Sharsheret's founding in 2001, we have responded to more than 25,000 cancer inquiries, involved more than 1,650 peer supporters, and presented over 250 educational programs nationwide. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life.

All Sharsheret's programs are open to all women and men and Sharsheret is the beneficiary of funding from the federal government.

Sharsheret offers the following national programs:

The Link Program

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

IX. Disclaimer

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

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