

How Does Breast Cancer Affect Young Women of Diverse Backgrounds?

**Transcript of the National Teleconference
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Presented By:

Sharsheret

Linking Young Jewish Women in Their Fight Against Breast Cancer

Young Survival Coalition

Young Women United Against Breast Cancer

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I. Part One

Stacy Lewis: Good evening, everyone. It is a pleasure to have you here tonight. I'm Stacy Lewis, the Program Director for the Young Survival Coalition, and I will simply welcome you on behalf of the Young Survival Coalition, the only international nonprofit organization focusing on the unique issues of young, premenopausal women diagnosed and dealing with breast cancer.

It is our pleasure to work with Sharsheret on this wonderful teleconference, and we look forward to offering many different aspects and interesting programs focusing on issues of diversity. So without further ado, I will turn it over to Rochelle Shoretz, Executive Director of Sharsheret.

Rochelle Shoretz: Thank you, Stacy. Welcome, everyone. I am the Founder and Executive Director of Sharsheret, which is a national not-for-profit organization supporting young Jewish women facing breast cancer. Sharsheret is the only culturally-sensitive organization addressing the needs of Jewish women who have been diagnosed with or are at risk of developing breast cancer. So, tonight's conference addressing diversity and our collaboration with the Young Survival Coalition is particularly meaningful.

I invite you all to visit our web site, www.sharsheret.org, to learn more about our programs, services, and publications including some new programs we have recently launched addressing the needs of caregivers, young children, and women living with advanced breast cancer. It is now my pleasure to introduce Khadijah Carter who, along with Sharsheret's Program Director, Elana Silber, has really shaped tonight's teleconference.

Khadijah Carter: Thank you, Rochelle. My name is Khadijah Carter and I'm a three-year breast cancer survivor and the Diversity Coordinator for Young Survival Coalition. YSC's Diversity Program aims to reach diverse populations in an effort to provide young women affected by breast cancer with a committed, connected and diverse community. The purpose of this teleconference is to address the unique ways in which breast cancer impacts women of diverse backgrounds, issues, and concerns of each unique population, the cultural disparities in breast cancer treatment and how we can help medical professionals and patients address this disparity.

We have 11 panelists consisting of health care professionals and advocate survivors who have graciously taken the time to be with all of us tonight. Tonight's call is being recorded and a transcription will be made available on the Young Survival Coalition's web site, as well as Sharsheret's web site. That's www.youngsurvival.org and www.sharsheret.org.

The format of the call is as follows: Each presenter will impart his or her

knowledge and experiences to help you and healthcare providers understand the unique needs of breast cancer survivors. The segment will be in this order: African American, Asian, Jewish, Latino, lesbian, and metastatic. Questions will be taken midway through the call and again at the end of the call. If we run out of time and you still have questions for the panel or wish to receive full bios for the health care professionals, you can submit them through diversity@youngsurvival.org. We will do our best to get an answer to you.

Now, I'd like to tell you a little bit about our first panelists who are representing the African-American community: Dr. Funmi Olopade and Angela Pittman. Dr. Funmi Olopade is a professor of medicine and Director of the Center for Clinical Cancer Genetics where she directs a multidisciplinary clinical and laboratory research program at the University of Chicago Medical Center. Dr. Olopade is internationally renowned for her expertise in breast cancer and has been published extensively in the area of genetics of cancer predisposition.

Angela Pittman lives in Los Angeles, California. She was diagnosed at the age of 33. Her aim is to increase the awareness of breast cancer in young African-American women. Dr. Olopade, you have the floor.

Funmi Olopade: Good evening. It's really a pleasure for me to be here and I just want to share a few things with women out there. I do practice medical oncology and I take care of young women with breast cancer of all ethnic and racial backgrounds and in particular women who may have a strong family history of the disease. One thing that really gives me an insight into how African-American women deal with breast cancer comes from the location of my practice, which is on the South Side of Chicago.

When I'm trying to get my patients to think about breast cancer, uniformly one of the issues that come up is well, Dr. Olopade, you have to get me to see my daughter's wedding and to see my son graduate. So, young women are really thinking about their future. They're not thinking about dying from breast cancer. So I think that they want to make sure that the doctors that are taking care of them are looking beyond what is standard of care to doing something that would be uniquely more effective for young women. At the same time, they're also dealing with the shock of a diagnosis and they're juggling family life, they're juggling work if they are employed, and then they're juggling what will their friends say about not having any hair, being bald, their self image.

So I spend a lot of my time really just saying, "Look, there's life beyond breast cancer. You can be beautiful even while we're treating you. But first things first. Let's treat you, let's get this cancer out of you, and let's look for a long future of good health." So I think that from my perspective young women really have to find doctors that are going to be there for them, that are going to be optimistic with them and are going to be hopeful that they in fact beat the disease, no

matter what stage they're diagnosed. I think that's what I'm going to start off with unless someone else has something to say.

Khadijah Carter: Angela Pittman, you can respond to Dr. Olopade.

Angela Pittman: Briefly, I'll tell my experience at the age of 33. In 2002 I was diagnosed with stage IIa invasive ductal carcinoma in situ. I had a right breast mastectomy with four rounds of Adriamycin and Cytoxan followed by tamoxifen, which I was on for two years, two-and-a-half months. On May 19, 2005 at age 36, I was diagnosed with metastatic breast disease, distant recurrence, with mets to my liver and lymph nodes of my abdomen, chest and my neck. I started with four rounds of Taxotere and I'm currently on Taxol with Avastin three weeks on, one week off.

For me, I could definitely say that I've been blessed as far as my medical team being quick to act, ordering all the necessary tests, and I feel really good about the treatment that I'm receiving to help me live a long life. I know I'm blessed and that maybe some young women ... what I really want to say is that I'm proactive. I take an active role in my health care. I know a lot of young women especially in the African-American community that are, say, low income, some people are afraid to ask questions, and they're accepting of what maybe the doctors are saying.

I know that I would just definitely suggest educating themselves, asking all the questions that you need, and, like Dr. Olopade said, finding a doctor that's optimistic about your health and working with you to help you fight this disease, which is what I have in my medical team. For the medical community it's like a lot of them are still with this whole, "You need a family history and you're not old enough to get this disease," is changing their mindset. Because I've gone into the emergency room before and doctors have been like, "What do you want tamoxifen for? You're too young to have breast cancer." But it affects young women everyday. So for me, the medical community, sometimes they need to change the way that they think.

Some young women in African-American communities don't know what resources are available to them. Maybe reaching out to the local hospitals, because a lot of them who are uninsured go to county hospitals, making sure that they know what's available to them, because a lot of them don't know. For myself I am all about empowering myself with educating myself and really working with my medical team to help me live a long life.

Funmi Olopade: The only thing I'm going to add is that the breast cancer that we treated 20 years ago is no longer the same as what's going on in 2006. I'm constantly saying the myth out there is that breast cancer is a death sentence and so women are so afraid, they're so anxious. When they feel that lump they

don't even want to go out and do something about it. I have to say, "Look, this is something that, there's no point burying your head in the sand. Just face it head on." We're saving more lives. Even when the cancer is metastatic you can still have a very long life with good quality. The important thing is to just go in, get treated and have a doctor who is going to be a partner with you.

Angela Pittman: Right. I definitely agree with that one.

Khadijah Carter: Thank you, Dr. Olopade and Angela. We're going to move on to the Asian segment of this call. Our first panelist is Rebecca Sze. She is the Director of Women's Health Services at the Charles B. Wang Community Health Center, where she oversees the delivery of comprehensive quality health care to Asian women. Her vision of comprehensive women's health has been focused on preventive care, patient education, and community outreach. She has been collaborating with various community organizations to ensure that culturally sensitive services are available Asian women.

Kristine Tanno lives in New York City and was diagnosed at 35. She is an active advocate for raising awareness about and advocating research for breast cancer in young women in ethnic minorities. Personally she tries to share her story as an unexpected face of breast cancer: Japanese American, under 40, healthy lifestyle. Rebecca Sze, the floor is open.

Rebecca Sze: Hi, great. Thank you. Good evening, everybody. Just like the introduction says, my focus and my vision is to help the underserved women, especially the Asian-American women in New York City, to be more aware of early detection and then also empower them to go through the screening as scheduled. We also provide case management.

So far the challenge that we've been facing for the group of women that we serve, most of the women who come to us, they're undocumented as well as uninsured. When we identify any kind of suspicious finding, one of the challenges that we have is to help them go through the western medical system. Because a lot of them, they still bring in a lot of beliefs from where they were from, such as Malaysia, China and that they can try some kind of herbal medicine, maybe that will help and then we delay the care.

Then the true challenge that we've been facing with the women who are being diagnosed with breast cancer is to have adequate family support. Because the woman is the main supporter for the family in the Asian culture and most of the time they feel that if they become sick, they will no longer be able to serve their family.

So to try to have them go through the level of adjustment, body image, as well as take them all and prevent them from getting into depression, that is another

challenge for us. Then number three, since they are undocumented and a lot of them, they fear participating in the health care system, and then suddenly you are unable to locate them, they disappear. Hopefully, they will try to get some kind of health care either back in their country or do some kind of private pay or something like that, but they're just lost in the system.

So those are the three big challenges that we've been dealing with in serving the Asian-American women in New York City. But in terms of young survivors, as I have mentioned to the group before, most of the survivors that we have are above 40. I can count about two to three who are less than 40. But it seems that the challenges are almost the same across the age groups.

Khadijah Carter: Thank you. Kristine?

Kristine Tanno: Yes. My situation is a little different. I speak for me and the friends that I have who are also Asian American, Indian American, Chinese, Japanese, and I found it interesting that we had similar experiences. A number of my friends actually did not disclose their situation to their family. And I think that that was very difficult for other cultures to understand and appreciate, because their perspective was that clearly this is a big thing going on and wouldn't you want your family to support you.

What I found is that half of my Asian friends actually did not disclose it to their parents. They maybe told a sibling. But their real concern was not putting a burden on their parents and not having them worry so much, and as a result, they really relied on an internal support network to be able to discuss all of their concerns and so forth.

I think that is something that I don't see across other cultures, this need to keep the information close at heart. I also think on the flipside, there is sometimes emotionally in terms of the culture, a difficulty in addressing the shock and being very expressive and discussing their fears and the concerns and so forth. So that was the other topic that we used to think about and actually openly discussed within the peer group is to say I don't feel as comfortable talking about this.

I spoke to one person. My doctors would always call me and say, "Can you talk to this person? They're Asian." And I found that really surprising that I got called so often, but essentially, they were saying, "Look, can you talk to this person and basically just listen to them because they don't have anybody else to speak to."

To me this is sort of concerning and it's unfortunate but I do think that, again, it's an Asian cultural thing sometimes but even within a family with a lot of breast cancer, they don't really discuss their feelings, and it's frowned upon to kind of go through these highs and lows of emotional expression. So it's something that I

think is distinct about Asian culture and unfortunately, isn't brought up. But at the same time it's great to have peers, and I think that the YSC has done a great job in terms of connecting people.

Khadijah Carter: Any comments, Rebecca?

Rebecca Sze: Christine, you should be glad that you can help them, serving as the patient advocate.

Kristine Tanno: Absolutely. But I think that it's one of those things because we're younger, we don't necessarily have friends who have gone through similar experiences.

Rebecca Sze: Exactly.

Kristine Tanno: So at this age group, we don't have that necessary support network. I think from a cultural standpoint, it seems at odds. If you were to, for example, break your leg, you would tell your parents. But if you have cancer ...

Rebecca Sze: It's different.

Kristine Tanno: It's a whole different level of what you would express. I think it's hard to go through alone. It's hard to go through without your family knowing it and trying to hide it. So it's an added burden to deal with. It's also a challenge if your family can't deal with it as well and can't express their concerns because it creates an emotional divide.

Rebecca Sze: Those survivors who seek your help, most of them, are they born in this country?

Kristine Tanno: It's a mix actually of both, and it's across different Asian cultures. I think for the doctors, they don't know the difference between the cultures either. So they think, "Oh, this person is like you." There's a big difference between a first generation and a third generation and what you feel comfortable talking about. I don't know if this is the case as well, but I think that also their questions about fertility and sexuality, and there's also a stigma associated with something genetic that your family or your genes have been polluted in some way and that they don't want to disclose that as well.

Rebecca Sze: I see.

Khadijah Carter: Thank you, ladies.

Khadijah Carter: We're now moving on to the Jewish segment. Dr. Freya Schnabel is a graduate of Barnard College and the NYU School of Medicine

where she was elected to the Alpha Omega Alpha Honor Society. Trained in surgery at NYU Medical Center, Dr. Schnabel limits her practice to breast cancer. She is the Chief of the Section of Breast Surgery at Columbia Presbyterian Medical Center and is the Vivian Milstein Associate Professor of Clinical Surgery at Columbia University College of Physicians and Surgeons. Dr. Schnabel is the Medical Director of Women at Risk, the high-risk breast cancer program at Columbia Presbyterian Medical Center. She is also the Vice-President of the newly formed International Society for Cancer Risk Assessment and Management. She has contributed to the medical literature on breast diseases and lectured extensively to professional and lay audiences on this topic.

Rochelle Shoretz lives in Teaneck, New Jersey and is the Executive Director of Sharsheret, a not-for-profit organization she founded to connect young Jewish women fighting breast cancer, following her own diagnosis at the age of 28. Rochelle is a four-year breast cancer survivor, an attorney, and the mother of two boys, ages ten and eight. Dr. Schnabel?

Freya Schnabel: Good evening, everybody. I want to thank the Young Survival Coalition and Sharsheret for organizing this very worthwhile discussion this evening. I think that this is an intriguing topic. When I think about the population of young Jewish women with breast cancer, I think there are three major issues that we face with this population.

The first one is genetics. As was alluded to just a couple of minutes ago, the fact that we are learning more and more about breast cancer genetics, and particularly about breast cancer genetics in the Eastern European Jewish population, is exciting and is ultimately going to help us protect women who have cancer and women who are at risk for breast cancer in a much more informed way.

However, there are all sorts of problems that are engendered by the idea that cancer can be a disease for which you can get an inherited susceptibility from a parent and have this passed down through the genetics from parent to child, creating many, many, many issues within families regarding the feasibility of being tested, individuals who are interested in the information, individuals who are not interested in the information, people who have opinions on whether other people should be tested or not, certainly guilt on the part of parents who are found to be the source of genetic mutations and so on, and I think that this is a particularly striking issue in the Jewish community, simply because of the increased prevalence of these genetic mutations, particularly in the Eastern European Jewish community.

So as a whole I think young Jewish women with breast cancer face this unique situation, and we are still struggling to find ways to help people cope with the potential diagnosis of an inherited susceptibility to breast cancer. That means

helping the patient involved and also helping the entire family to cope with what can be very devastating news.

I think the second category of particular issues for young Jewish women with breast cancer has to do with fertility, particularly in the Orthodox Jewish community. This is a community of religious Jewish women that Sharsheret has made enormous, enormous strides in reaching out to. I really compliment the organization on that level.

In this community particularly, fertility and having a family and the number of children are very, very, very important qualities and many times women who don't have children or women who have very small or limited families are set apart from the mainstream of the population. This can be, again, an enormous burden for a woman who is struggling with a cancer diagnosis and also struggling with something that seems to alienate her and set her apart from the community at large, not allowing her to share in the same occupations and concerns that many, many of her friends and neighbors and associates may be sharing in.

That's a very tough thing for people already struggling with the disease to have to also struggle with ways in which the disease impacts their life and makes them not able to participate in the life and the activities of the community in the way that they would like to. Again, I think advanced fertility methods which at some point maybe somebody is going to talk about or get into, that are now becoming available to younger women with breast cancer are really exciting and may go a long way to easing this burden. But for women whose fertility has been interrupted or impacted or even completely done away with by the breast cancer diagnosis, this is something special that we health professionals need to be very attentive to and aware of.

I think that the last little sort of special consideration that I've seen in women in the Jewish population that I've dealt with who have breast cancer, particularly again in the Orthodox Jewish population, is something that many of the speakers and the participants in tonight's conference call, I think this will resonate with them. Because in many communities that are small or tight knit, one of the issues for young women with breast cancer, like with any other disease, is stigmatization.

It is not just the difficulty of coping with cancer diagnosis, but negative implications that may arrive for the individual and for the family. Patients are very concerned that other individuals in the community perhaps not be made aware or find out about their diagnosis. They're afraid that people are going to look at them differently, that there will be some sort of stigma attached to themselves, stigma attached to their children or the remainder of their family, that once again they will never be able to live their lives in a normal fashion without having this somehow impact every single day's existence.

This is, as I said, something that I have a feeling we're going to hear about from lots of other members of different small communities, because it's something that's shared by lots of individuals who are part of small, tight-knit communities. But I do think that we need to work a lot harder at making all of our patients understand that there's nobody out there who doesn't have some sort of a situation going on in their family, with their family history, with health history or with other situations and that the stigmatization is a burden that they shouldn't have to have along with the burden of having a disease. If we encourage a little bit of openness and honesty among everybody in small communities then maybe we can ease this burden particularly for our patients with breast cancer.

Khadijah Carter: Rochelle?

Rochelle Shoretz: Hi, thank you. This is Rochelle. I was diagnosed four years ago at 28. I'm an attorney and at the time I was raising two young boys who were then six and four years old. At the time of my diagnosis, I was actually diagnosed at stage II. I had a lumpectomy then chemotherapy and I'm currently taking Tamoxifen.

I know that before my own diagnosis and before my work in founding Sharsheret, I didn't know a single Jewish woman under 30 with breast cancer. Jewish grandmothers, most definitely, but younger Jewish women, I didn't know even one. I've come to believe that more frightening than living with cancer is believing that you're the only person like you who's living with cancer. So I struggled to find others who shared not only cancer with me, but also my life background: Women who could understand what it would be like to use the mikvah, which is a Jewish ritual bath that married women use each month, after my own lumpectomy; women who could understand what it would be like to prepare for the Jewish high holy days, when we pray for another healthy year, in the midst of my own chemotherapy; women who could understand the fear of living in a population of Ashkenazi Jewish women, like Dr. Schnabel identified, who are at increased risk of carrying a mutation in the BRCA1 or BRCA2 genes.

By far the most frequently asked question I field about Sharsheret is: In what ways is the breast cancer experience different for Jewish women? Of course women of all religions and cultures share common concerns in fighting breast cancer. We're all going to experience the fear, the pain, sometimes even the joys of appreciating what we once took for granted. But I'd like to highlight some of the ways in which breast cancer was challenging for me as a Jewish woman and for some of the other women who have phoned Sharsheret, and some of these are issues that Dr. Schnabel has already identified.

First, religious ritual. As I mentioned before, using the mikvah bald during chemotherapy or with an altered breast after surgery can be traumatizing for a lot

of the women who call the organization. Women often have altered feelings about sexuality that arise around the time of treatment and around the time of mikvah, which again is the ritual bath that married women use. So for some Jewish women, just the actual practice of religious ritual is affected by surgery choices and treatment choices.

Second, the role of the community is one that a lot of women, and particularly myself included, feel very strongly about. The close-knit Jewish community that you can find in some areas can be a wonderful source of support. But it can also be confining for some women who don't want to share this very personal experience with others.

Third, the role of religion in daily life with cancer. Some women draw tremendous comfort from religion while others who are newly diagnosed really struggle to understand their diagnosis in a religious context.

Fourth, I would identify hair covering. Many assume that wearing a wig during chemotherapy must be easier for those Orthodox Jewish women who cover their hair after marriage. That's a common practice in the Orthodox and the Hasidic community. But wearing a wig or a hat because you've embraced a religious ritual is actually quite different from covering your head because you lost your hair to cancer. For single women who are Orthodox or even for single women who are of any Jewish background who have to cover their heads, wearing that which is typically associated with marriage in Orthodox communities only complicates already complicated emotions.

And finally, most commonly, what Dr. Schnabel has already identified is breast cancer genetics. I think it's estimated that one in 40 Ashkenazi Jewish women carry a mutation in the BRCA1 or BRCA2 gene. That's a frightening statistic for Jewish women like me, and one that we want research scientists health care professionals to explore in the years ahead. I'll make one final point about access to breast cancer services to say that for many Hasidic and ultra-Orthodox Jewish women, merely speaking about breast cancer is taboo. And that's something we've heard from Kristine, for example, in other cultures and other communities.

Breast cancer is a conversation they choose not to have because of fears that they have about how it will affect their children's ability to find a suitable marriage partner, for example. So for these women access to breast cancer services is limited often by their own choices, and Sharsheret has been working closely with the Susan G. Komen Breast Cancer Foundation to bring health education to these communities within the tri-state area.

What can health care professionals do to address the concerns Jewish women have in facing breast cancer? Well, first, I would suggest familiarizing yourself

with some of the issues we've highlighted this evening. Sharsheret has published three booklets that can be very helpful in understanding the concerns of Jewish women. They include Facing Breast Cancer as an Orthodox Jewish Woman, Facing Breast Cancer as a Jewish Woman, and Breast Cancer Genetics and the Jewish Woman. And those booklets can be ordered online at www.sharsheret.org.

Second, I would suggest that we all respond with sensitivity to the lifestyle of those we serve. If you're meeting with a Hasidic woman, consider that she may not feel comfortable receiving materials from your office in an envelope that's clearly marked with the words "breast cancer." If you're meeting with a young woman, consider that she may be very concerned about the impacts of treatment on her fertility in a community that stresses child rearing. If you're meeting with a Jewish woman who has a family history of breast or ovarian cancer, consider taking the time to discuss genetic counseling and genetic testing and not merely assume that these women and these families are already familiar with those options.

I'm actually going to close with a reflection I recently heard from a doctor. I had explained to him that I was upset that one of my sons had begun to notice that he's different from other boys his age. The doctor explained to me it's only when we begin to recognize that we're different in some ways from each other that we can truly say we're a part of the greater community. I think the same holds true for all of us tonight facing breast cancer together.

Khadijah Carter: Thank you, Rochelle. I will actually turn over this portion of the call to you because you're going to be the moderator for the Q&A.

II. Question and Answer Session

Rochelle Shoretz: Thank you, Khadijah. Some questions have already come in and so Angela, the first question goes to you. Someone has asked the following question: You spoke about the medical system and how many uninsured or low-income women end up in county hospitals. Do you have any guidance about how to put a health care team together when you don't necessarily have adequate insurance coverage or the kinds of health care that you might find in other communities?

Angela Pittman: I've heard with like Medicaid or something it's possible to be able to go to an HMO because, say, Kaiser out here in Southern California accepts Medicaid, so that maybe you don't have to go to a county facility or a local hospital. There are ways to go on the Internet, if that's available, like the American Cancer Society to see if there is a way to be able to put together a health care team that will help you with your health. That's one way to address it. A lot of the facilities have social workers, talking to them to help put together a health care team that you feel confident working with.

Rochelle Shoretz: Thank you, Angela. Dr. Schnabel, the next question is for you. A young woman wrote in actually in advance of the conference. She was diagnosed at 22. Her mother was diagnosed 15 years later at age 71. She was told that genetic testing might be a viable option for her. She's not sure if she should pursue this option. Since you touched on genetic counseling and genetic testing, perhaps you might just summarize quickly what you believe to be the criteria for someone suitable for genetic counseling or genetic testing.

Freya Schnabel: I think that's a great question. And I think it's going to be relevant to a lot of our different callers that are going to be participating tonight. I think that the criteria for genetic testing are a little bit fluid in terms of there being no absolute definites about testing for most women. There are a couple of points, though, that I would make. A family history that suggests that a genetic mutation may be operating in the family would look like this. There would be lots of women with breast cancer over multiple generations, many of those women would be premenopausal at the time of the diagnosis and there would be a number of them with bilateral breast cancer.

You might also see within the family more of other cancers and particularly ovarian cancer. When ovarian cancer is seen in a family together with breast cancer that's very suspicious for the genetic mutation being present. Now for women who are considering going forward with genetic testing, it's important for them to think about what are the potential benefits to them of doing this and what are the potential downside risks. Certainly the benefits are clear in learning information that could help you protect yourself against the potential risk of not just breast cancer, but also ovarian cancer.

That may not be within the scope of our conversation tonight to really talk about that a great deal, but I think many of us on the call are aware of the fact that ovarian cancer is a disease that's very difficult to diagnose early and as a result, presents a large health risk. When a woman is tested for the BRCA1 or 2 genes and found to be positive, the increase in risk of both breast and ovarian cancers needs to be discussed.

But relevant to the caller or the participant who asked the question, I think there's one more thing to say. It's really, really good medical practice never to ask a question unless you're actually interested in the answer. Women who are contemplating genetic testing should be counseled to the point where they are prepared to make decisions based on the results of that testing. It's not in anyone's best interest to do the genetic testing and then for a woman to be horrified, overwhelmed and unprepared to make any active decision regarding the management of her increasing risk of breast and/or ovarian cancer.

So this is always done through the mechanism of genetic counseling. A genetic counselor is always involved to help individuals understand the implications of testing and what the testing may or may not show and make sure that women who go forward with the testing are very well prepared to deal with whatever the results may bring.

Rochelle Shoretz: Thank you, Dr. Schnabel. Another question came in and I'd like to address this one to some of the younger survivors who have already spoken. Someone has written, there are often diagnostic delays in young women. They go to the doctor and then they're told that they're too young and should come back only to discover of course that they've been diagnosed with breast cancer. Has that been the experience of anyone who's spoken thus far?

Khadijah Carter: I felt my lump in December of 2002. I saw my gynecologist in January 2003. Initially he didn't think anything of the lump that I had. He said, "Oh, you're probably too young". So he scheduled me to take a breast sonogram for the following month, which was February. The results of that were a little suspicious, so then I was set up for another appointment in March for the needle core biopsy. I didn't get diagnosed until the beginning of April. So from December until April, my tumor grew rapidly.

So I can definitely attest to that statement. I always think about it as if I didn't follow-up, if I just said, oh, forget about these appointments, I don't know what would have happened because by the time I was diagnosed I was already in stage III. So I do find that that is a problem. Sometimes health care professionals don't believe that you could have cancer because you're so young and they do delay your test and need to understand that there's a possibility that something could be wrong.

Kristine Tanno: This is Kristine. I had a similar situation and I know a number of other young women who also had similar situations. I think that for me personally, I went in and I had actually hurt myself and I was told that it was a blood clot and to monitor it for the next three months and if it didn't go away, then we would address it. And so clearly that was incorrect. It was a tumor. And I know that a couple of my friends also have had the same situations. Essentially what they did was they were persistent and insisted upon getting it checked and that's where it made the difference.

And like Khadijah, I have a friend who was stage III, I was stage II, but it was very, very close to becoming stage III. So I think had none of us persisted, we would be potentially in different situations.

Khadijah Carter: Right. We have to be proactive.

Rochelle Shoretz: Okay. The final question I'm going to take myself because it's addressed to me. But I also encourage everyone to continue to stay on. We still have presentations that remain and there'll be another question and answer session at the end. The question that came in is whether or not there were resources specific to Jewish women that one might access. There certainly are and you can access those on Sharsheret's web site, which is www.sharsheret.org. But I'd also like to highlight that both the Young Survival Coalition and Sharsheret have on their web sites interactive forums where women can actually ask and answer questions and help each other by recommending resources. I think that's a wonderful way to really tap into a broader network.

I encourage everyone to visit both of our web sites and hop on to the interactive forums and share resources with each other that way. If you'd like to contact us, somebody asked how to contact Sharsheret; again all of our contact information is on our web site. Khadijah, at this time I'll turn it back to you for the remainder of the presentation.

III. Part Two

Khadijah Carter: Okay. Thanks, Rochelle. We are now moving onto the Latino segment. Dr. Jenny Romero is a medical oncologist at the Ralph Lauren Center for Cancer Care and Prevention in New York City. She is also a clinical affiliate in the Department of Medicine at Memorial Sloan-Kettering Cancer Center and attending at North General Hospital.

Dr. Romero was a member of the North Eastern Regional Executive Committee of the Surgeon General's National Hispanic/Latino Health Initiative, a program designed to identify and prioritize critical health issues facing Latinos in America and to develop and implement strategies to address these issues. She's particularly interested in research that focuses on identifying the factors that contribute to the poor prognosis among African-American and Hispanic patients diagnosed with cancer.

Ivis Sampayo resides in New York State and is the director of LatinaSHARE, self-help for women with breast or ovarian cancer. She's a 12-year breast cancer survivor, diagnosed at 38 years of age. Dr. Romero?

Jenny Romero: Hi. I'd like to thank you for inviting me. My interest, as she mentioned, lies in cancer health disparities and I work with a large population that are either uninsured, underinsured or have Medicaid. My population is basically ... I'm right in the middle of East Harlem in Harlem, and 76 percent of my patients are either African American, Caribbean Black, African or Latino with half of my patients being Latinos. That's just a little bit of what I normally see every day.

In terms of breast cancer among the Latina population, we actually have almost 40 percent lower incidence than Caucasians in this country. The problem really lies in the fact that there are so many barriers to us getting health care here and it even seems more exaggerated among the younger population. I tend to look at barriers in our communities in four ways. There seem to be financial barriers. There seem to be cultural barriers, physician-related barriers, which are very real and often not talked about, and fears and information barriers.

So in our community, what I generally see is about one in every three Latinos or Latinas is going to be uninsured. We have a much higher uninsured rate, which is a major problem. We tend to hold jobs that don't give insurance, and many times because we also have an undocumented population, have very difficult time getting even Medicaid. It's not that we don't come in, because the interesting thing is at my center, one of the things that we do is we have grants for free colonoscopy, free paps, free mammos for people who qualify financially. For those who don't, we have low cost.

I do a lot of outreach, and I do a lot of outreach both in English and in Spanish. I do it on TV, radio and so forth in the community. Whenever I get on the TV,

Spanish TV, I got to tell you, we get swamped with calls. The Latin woman wants to come in or the Latina wants to come in and get screened for cancer. They just don't know where to go. Many are uninsured.

There is also the added problem of: If you don't work, you don't get paid. So there are a lot of financial barriers, not just lack of insurance. In our community also, there are a lot of informational barriers. A lot of the information is done in a very un-culturally sensitive manner. There are a lot of problems navigating through the system when you don't speak the language. Many times we really don't know where to go to get that mammo if you find a lump.

Unfortunately, one of the things I see a lot is the inappropriate use of family members as interpreter. There has been a ten-year-old kid interpreting for the mother that she has breast cancer. You can imagine how horrible, how frightened that kid would feel. Many times also the family member who's interpreting doesn't want to tell the patient. So I have patients who don't know and the first thing ... this actually happens quite commonly. "Oh, don't tell them that they have cancer because they're going to die quicker."

There are a lot of cultural barriers in our community, a lot of myths concerning cancer in terms of screening also. I don't have to screen it if doesn't run in my family. Breast cancer probably comes from mammography. Cancer comes from God's punishment, so there's nothing you can do for me. This is my fate; this is my punishment. So any treatment or what have you isn't going to be effective. Cancer can also come from a fufu, la Santeria, some hex that somebody put on you.

Many times I hear patients who don't want to get the biopsy. Why? Because if you get oxygen on that tumor, forget it, it's going to spread like wildfire. So people will not seek treatment because of it or refuse treatment. There's a very big fatalistic view in our community. There is also a big image barrier and it's very cultural. Women are supposed to have long hair, we're supposed to have breasts. What is our husband going to say? Or if I'm going to get treatment I have to get my husband's permission. So that can be very difficult, and a lot of times you're negotiating with the husband whether or not the patient's going to have, you know, the surgery and the chemo.

Fear is very big. And as someone mentioned before, people don't want other people to know, because they're going to be ostracized or people are going to treat them as if ... the idea is that cancer is catchy. So they keep it as secreto or secret because if somebody finds out, they're not going to want to deal with me. And shunning from the community also happens in our community. I say "our community" because I'm also Latin.

There's also fear of deportation. People do not want to seek medical care

because they'll have to give information and they may get deported. One of the things we don't speak about often is physician-related barriers. A physician may not screen, particularly a young person. I had a number of young patients unfortunately in their 20s and 30s with breast cancer. Quite a number of them had difficulties obtaining imaging or a workup for their lump because their primary care physician or their GYN has felt, "Oh, you're too young."

There is also the problem with treatment in our community. Latinas unfortunately are less likely to get a lumpectomy. They're more likely to get a mastectomy. They're also less likely to get radiation when it's indicated. We're less likely to get hormonal therapy when it's indicated. So there is a very big disparity among certain minority groups in terms of the care they receive. It's not just Latina. I see it very often among African-Americans also. I end up having to clean up other people's lack of work.

There is also a lack of subspecialties in many minority communities. So you may have someone with ovarian cancer who would be better operated on by a GYN oncologist, which, studies have shown, do a better job of it. But you're going to get treated by the regular local GYN and you see a little bikini incision, which is inappropriate. There is a lot of cultural insensitivity among physicians towards people who are different.

I've experienced it as a medical student. I was translating for a doctor when I was a medical student. I related why the patient wasn't compliant because she had really bad arthritis and couldn't afford the taxi. She couldn't afford the taxi and just couldn't take the bus because she was in pain. He told me, "You can't trust anything a Hispanic says during an interview."

So there are a lot of barriers in our community and a lot of preconceived notions about compliance, which is one of the things we work at really hard at Ralph Lauren, both in terms of the physician and in terms of our population to hopefully desist. That's it.

Khadijah Carter: Thank you Dr. Romero. Ivis?

Ivis Sampayo: Hi. My name is Ivis Sampayo, I'm the director of the LatinaSHARE program at SHARE, Self-Help for Women with Breast, Ovarian Cancer. I was diagnosed at the young age of 38 and I had been complaining since I was 36. Listening to everyone who's speaking today, it's amazing how there are so many things that happened to all of us or have had happened to all of us that are very common.

My doctor didn't believe, since I didn't have a family history and didn't have any of the known risk factors, that I could have breast cancer and I didn't have a lump per se. I just had these sensations on my breast. And since I was nursing, I had

just finished nursing my son; he figured that it had some sort of a relationship to that.

When I was diagnosed my children were two and ten. And I speak the language. I'm of Hispanic origin and the first thing I thought is, after I finally got diagnosed, "Oh, my God, what about countless women that don't advocate for themselves, don't understand the language?" Whether they spoke Spanish, Italian, Greek, it didn't matter. The fact was that people were not advocating for themselves because the majority felt that the doctor knew best, with all respect to other doctors on this teleconference.

But, anyhow, this made my life a completely different one. I decided that I had to become an advocate that I had to become involved. I wound up with a lumpectomy, chemotherapy. I had Adriamycin for three months, CMF for six months, radiation and hormone treatments, Tamoxifen for five years.

I've been with SHARE now for about ten years and one of the things is working there that I've seen so many of the issues that Dr. Romero just spoke about. I won't repeat them all, but again with the Hispanic community much of what's happening is you're dealing with communities within communities. We have communities that are coming in from Central and South America. Many of the immigrants have issues with respect to, of course, being uninsured, how to pay for their treatments, if they're undocumented, they're afraid of the deportation.

Another thing is, and I know not so much here but in other states, it's the mobile population, where they can come into a clinic and finally get diagnosed and start the process and then leave midway and then return back to their country.

Other issues that happen are that they don't self-advocate. And I don't want to stereotype, because again, this all depends on where they're coming from and their generation. As one of you had mentioned, each generation can be different. I was born and raised here so I knew to speak up for myself. But two generations ago, they did not. My grandmother would not ever have questioned a doctor and a diagnosis or anything. You don't question the doctor.

As Dr. Romero mentioned, language barriers. That's a big one. But also one of things is that the stigma of cancer in some Hispanic communities, many, especially the immigrants, it is still there. They're at least ten years behind where the rest of the United States is.

Not knowing that they had a family history, that is also something that is very important to this community and many of them do not know. Many of them, again because of fact that it is a mobile population, others never spoke about the word cancer. Cancer was the Big C and you kept it quiet. So we do have young women that are coming in and they're being diagnosed with breast cancer and

the first thing they say is I have no family history.

I was one of them. I did not know until I had testing that I was a BRCA2 carrier. I have been born and raised here, I'm educated, and I'm involved in the breast cancer issues. I did not know that.

Some of the families support one another during this time; most of them do. It's almost "It takes a village" model; they support each other, they care for each other, they're also close knit. One of the things with this community is, just like in the Asian community, it was mentioned that the mother is the head of the household. She's really the one that keeps the family together.

They're afraid to get the treatment. They're afraid that they're not going to be able to take care of their family. One of the things that we do when I speak to them, when I go out into the communities is I tell them, you have to do this for yourself and your family. I try to use a role-reversal there because I was placed in that situation. I know what it's like to be there and say, "My God am I going to be there? Am I going to be there for that graduation or for that birthday party?" Then reminding myself that yes I want to be there, therefore I would do whatever it takes to take care of myself.

Some of the strengths: their religious beliefs. The fact that they believe ... in many cases, they're very strong within the community with the churches, and that helps them. That helps them in many cases. I'm sure in many communities, not just the Hispanic.

One of the ideas that we've come across with the LatinaSHARE program is the women that either call our hotline or become participants of our support groups is to educate them and to give them the opportunities to become advocates, to train them to become proactive. We're changing generations. I don't mean just the women that were born and raised here, because within our support groups, we have Latinas that speak English just fine. But they feel so comfortable within that culture that they decide to stay within these Latina support groups.

But we also have women that have come from Ecuador, Central America, Mexico who within their own countries or even their own homes, don't speak out, are now learning to become advocates. One of the issues that Dr. Romero touched upon is again with respect to the treatment and the follow-up. At SHARE we have the Survivor Patient Navigator Project that's located in two clinics in New York City. And we have survivors that are there, that are able to help the women at the moment that they're diagnosed.

One of the things that I really advocate for, as a Latina who was diagnosed at a young age, is that we need to speak out. I'm sure most of you will agree that once the media makes something important, everyone hears about it. And I think

that's an opportunity that all of us need to work with. We need to show the faces of young survivors, because we do want to be there to raise our children, to spend the time with our families, and to live a good, long healthy life.

This is one of the things that I speak about with the women that come to our groups, when we go out into the community, and we speak about it because they need to be heard. The stigma of cancer needs to be removed. It's really important and they need to know that they're not alone. Women call either a hotline and many get referred to Dr. Romero's hospital, to other hospitals like Bellevue, and we let them know, you do have a voice, you need to advocate for yourself.

Khadijah Carter: Thank you, Ivis.

Ivis Sampayo: You're welcome.

Khadijah Carter: We're now moving on to the lesbian segment. Anita Broccolino is currently the Development Director at the Mautner Project. She first became acquainted with Mautner five years ago as a client while going through treatment for stage IV lymphoma. Mautner was a natural step in her career after spending almost five years as an Associate Director in the Development Department at the Human Rights Campaign and National Marketing Manager at the Cystic Fibrosis Foundation.

Angela Powell lives in Denver, Colorado with her partner and children. She is a Health Administrator in the Public Health Service and was diagnosed with breast cancer at the age of 38. Tomorrow, February 2, she celebrates five years as a cancer survivor and continues her commitment to raising awareness about fighting this disease. Anita? Hello everyone and thanks for having us on the line.

We'd like to apologize, Amari was supposed to be on the call this evening and she took very ill and we're a rather small staff and we're all sort of cross-trained and I'm stepping in for the evening. The Mautner Project is a national lesbian health organization. For those of you not familiar with it, we started approximately 15 years ago strictly providing direct services for lesbians with breast cancer. We have since grown out of finding the need that there was a complete lack of lesbian specific health research and we now do advocacy training, etcetera.

We have one specific program, a CDC approved and accredited program, called "Removing the Barriers." It is a cultural competency training program that's used for medical providers. Basically we've trained well over 3,500 health care providers across the country in trying to explain the unique health concerns of women who partner with women. In my conversation here, I'm going to kind of

use lesbian, bisexual, transgender at times and other times women who partner with women as a way to just encompass the entire segment.

I think one of the things I would like to mention is, in all of the groups that are on this call, it is obvious there are lesbians that exist in literally every diverse population. So I invite everyone to either visit our web site www.mauterproject.org or call us if you have further questions beyond anything we discuss here this evening.

There are several unique risks for women who partner with women in the lesbian bisexual transgender women's population. They're less likely to go for their regular gynecological care for a variety of reasons. In doing so, they're missing their clinical breast exam. Many of them assume that if they're not sexually active with men, there's no need for a variety of tests including pap. They've had negative experiences with providers.

We recently did a study, Mautner Project in conjunction with Harris Interactive. We found that 40 percent of participating lesbian women in this study have reported delaying care at some point because they had past negative experiences with receiving health care.

Another important factor we find is insurance, obviously because same sex couples usually have less access to partner benefits than heterosexual married couples. In addition to all of this, there are also higher rates, there are a growing number of studies that have documented higher rates of smoking, obesity, alcohol consumption, all of those things obviously increase breast and ovarian cancer risks. I'm going to open it up to Angela and then to questions after that. So Angela, do you want you jump in at this point? Thank you.

Angela Powell: Sure. Good evening. As was mentioned, I was diagnosed at the age of 38 and that was about five years ago. You can do the math. And I sort of had the trifecta. I was under 40 and therefore I was presumed to be not at risk. I was African American, so I had certain health care-seeking behaviors that some of the other women have talked about, about just not wanting to know and not wanting to deal with and in thinking that some things will just pass. The third piece was, that I was a lesbian and who wants to go to the medical community after you've had a bad experience and have to come out all over again and do all of this explaining.

On the other hand, I was under 40 so I was still pretty mouthy. I was African American and I knew that no one was going to take care of me but me. And I was lesbian so I had a tendency towards advocacy. Fortunately I had been involved with the Mautner Project for about five years before my diagnosis. So it was one of those instances in which, unlike some of the other women have mentioned, I know a lot of women and especially a lot of lesbians who had breast

cancer and so it was almost a case of me knowing more than I wanted to know when it was my time to be diagnosed.

In my experience, I had asked for a mammogram from my primary physician probably a couple of years when I started to have some sensation around the age of 36. My primary care physician made the referral, but of course my insurance wouldn't cover it because I was under 40 and presumed to be not at risk. So once I found a lump she worked really hard and it was a little bit easier at that point to make sure I got a mammogram, went in, they did the mammogram, did a sonogram, called the radiologist in who wanted to do a needle aspiration. And of course I knew that once she inserted the needle and couldn't get anything out, that more than likely it was cancer.

But unfortunately it was another sort of negative incident because she said it didn't look as if it was malignant and that I should wait three months and then come back because I was under 40. She sent that back to my physician, my physician and I talked and we were both just furious. This is when I guess all three of my trifecta tendencies came out and we made sure that I got a surgical consult, had a lumpectomy and was in fact diagnosed with cancer.

A couple of things that I especially like to raise that I don't know that other folks have raised is that providers especially, I think with the lesbian population, need to have additional education around health care-seeking behavior and sensitivity to lesbians and the experiences that most lesbians have had with health care providers. Unfortunately, and I think this applies not just to lesbians but to women in general, sometimes, often times the physicians don't want to listen to the patient, they want to focus on the disease and not focus on the patient and they don't really engage the patient in decision making.

The thing I would say to patients and the thing that I did was I read everything I could on the Internet and in books that I could about breast cancer, the different types, the different forms, the different tests, the different treatments. So I insisted that I be included in every decision that was being made about my body. Fortunately most of my providers were willing to engage me on that and a large part of that was because of education I have received in doing this work before I was diagnosed.

With regards to patients, the last thing I would say is that if you don't take care of your body where are you going to live? And so you really have to learn. I would suggest learning as much as you can, trying to shake off some of those cultural beliefs we all seem to have about health care-seeking behavior and not wanting to hear bad news and in trying to step up and become an advocate.

I know it's hard. I think a lot of us, especially just women in general, don't do that. We tend to put everyone else's health care needs before our own. But

that's one of the reasons I'm on the call is to say you can be an advocate, you have to look out for yourself, and you have to demand good care. So, I think that's it for me.

Khadijah Carter: Thank you. We are now moving on to the metastatic segment of the call. Jill Cohen lives in Seattle, Washington, originally diagnosed at 39 and living with metastatic disease for three-and-a-half years since age 42. She is retired on medical disability and volunteers as a fundraiser and breast cancer advocate. Jill?

Jill Cohen: Hi everyone, I'm pleased to be included. I was originally diagnosed at aged 39. I had a small tumor and a lumpectomy, CMF, and radiation. I did develop lymphedema in the related arm after a life-threatening post-surgical infection. And that remains an ongoing issue of concern and something that YSC ought to deal with at some point.

When I was 42, I had a pain in my leg that didn't go away and after physical therapy and a referral to an orthopedist, it turned out that I had multiple metastases. I have metastasis in my skull, my sternum, which is the chest, both femurs, the thighbones, and along my spine. That same day, I fell and my leg broke, and so I had a long recovery from a big fracture in which to adjust to the concept of life with metastatic disease. My mets have also been treated with radiation and both my hips have been pinned, one to repair the fracture and one to prevent a fracture. So I have rods and pins in both legs.

I've been fortunate to be stable on aromatase inhibitors and Zometa for these past two-and-a-half years. However, I've had new mets develop in one hip and in both upper arms. They've responded to radiation and so I have not yet progressed to any kind of chemotherapy. A few weeks ago, I did have an oophorectomy to permanently induce menopause because of the side effect of Lupron, which was increased edema. And a woman with lymphedema cannot handle more swelling.

So the surgery pathology report from my oophorectomy indicated that I have evidence of metastatic disease on my ovaries, which I think is pretty unusual and I'll be getting some scans next week and talking with my doctors about any change in treatment if needed. So, I've been in touch with a number of women I know to talk about the issues involving living with metastatic disease.

Overall, I think that we look at a drastic and permanent change in our lifestyle when we hear the news that our disease has recurred and recurred at a distant site and in my case in innumerable distant sites. And so we have to find new meaning in life. So the issues range around health care, financial relationships and then death and dying.

To start with health care, I think for many women with metastatic disease or as we call it, "mets," pain management is a big concern because bony metastases can be quite painful. And all of us are always looking out for what's coming down the pike in terms of the latest new treatments. There are a number of women I know who are receiving off-label treatment for drugs that have not yet been approved for metastatic breast cancer because they seem to work. But how can you receive that if you don't have health care insurance?

A number of women who end with up mets end up losing their jobs or deciding to take that early retirement as I did. If you're fighting with your cancer and trying to figure out how to live with it, it's hard to have the energy for other things. So maintaining healthcare coverage or dealing with Medicare should one take disability and end up on Medicare and trying to find the best possible coverage is an ongoing issue.

For many women, after you've been on chemo unremittingly for years and years, you have chemo brain all the time. We also have the issue of sharpness and focus related to the inducement of menopause via chemotherapy or surgery. We're all much too young to be experiencing it and we don't have a flow getting used to it. It's a kind of zero to 60 in no time at all.

Other health care issues, and I think this is a very important one that's been spoken to before tonight, doctors need to be able to give bad news, but they need to learn how to do it well. It's not easy to tell someone that they have metastatic disease and to be able to do it with compassion and caring is the important way to go. And of course, we won't be cured. There's no cure for metastatic breast cancer, but we are alive now and we may live this way for many years and so we want to focus on living with our cancer.

Financial issues for women with mets have to do with balancing work, if you are still working, and living with a disease that could be disabling. Should you apply for disability? How do you handle the loss of income? If you're still working, do you feel trapped in your job because of the need to maintain your medical benefits? Then, if you're still working but you want to look for a new job because the current job isn't satisfying, how do you look for a job and not disclose your medical condition? On the flipside, what if as soon as you're hired you have to start asking for special considerations because of your medical condition?

I think there are specific issues around relationships and those would be partnered relationship, family and friends. There are real issues about sexual expression for women with metastatic disease and that might have to do with pain due to evidence of disease as well as the issues around mastectomy and lumpectomy scarring.

Then there are the issues of single women who have been diagnosed with

metastatic disease and are trying to date and find that life partner. For women who are parents ... and not all women with breast cancer are parents ... we want to be around to raise our children. We want to see each milestone. Because we are young, often our children are very young. I'm mindful of a friend who has children who are two and four. Of course she wants to live to see those children grow up.

When we have metastatic disease, we need an ongoing caregiver or maybe we need multiple caregivers. So tending to that relationship, no matter how difficult it may be, and the level of care that we need may change from the real basics of help getting in and out of the bathtub, all the way to just making sure you don't walk the dog too far.

We want to keep our marriages and partner relationships healthy and there is tremendous stress with ongoing cancer, living with cancer on a daily basis with really no hope for change until someone finds a cure. And then there's the issue of the destruction of personal dreams. Some of us hoped that we would marry, we hoped that we would have jobs that we love, and we hoped that we would be able to raise children. And cancer may have taken all of those things away.

And then the last, in terms of relationships, our friends, our family, and the people around us have trouble dealing with the fact that there is no happy ending for our cancer. We're not going to be done. We're always going to be in some kind of treatment.

Last, I think I want to speak to the issues around death and dying. No one has mentioned that yet, but when you have metastatic disease, you live with it everyday. I would recommend to women with metastatic disease that while you feel good, you should make end-of-life choices. You should be sure to write a will and address guardianship issues for your children, if you have any.

You need to have medical directives, so that your family, your friends, whoever is going to make that decision, knows what you want. And for those of us who don't have children, I would recommend writing an ethical will. This is a very ancient Jewish practice in the form of a letter, often to children but sometimes to family or to friends, listing the things that you value in your life, your life philosophy. I did this exercise when I was recovering from that broken leg, and it was very meaningful in terms of helping me decide what I wanted to leave as my legacy.

The other end of the death and dying issue is living while facing your mortality. It's a place of great tension, and most people in the world don't live there because it's too hard to face. But we who have metastatic disease, who worry about every twinge, have to learn to live there. And the last thing that I would say is that it's very important to think about dying a good death. A good death is one

where you have time to say goodbye, where you're surrounded by loving family and friends, and they have the chance to say goodbye to you. And that's a very important issue that I would hope that our physicians and social workers and our whole healthcare team would help us deal with and be there for us when we need to deal with it.

Khadijah Carter: Thank you, Jill. We now have time for a couple of questions and answers.

IV. Question and Answer Session

Rochelle Shoretz: Hi, this is Rochelle. Two questions actually have come in. Angela, I think you can take it, or Khadijah, maybe you could jump in, particularly from some of the younger women who have been calling in from the African-American community who have specifically asked for more particulars about the ways in which breast cancer affects women in your community and particularly both have also mentioned hair management issues after diagnosis.

Angela Pittman: Hair management meaning like, when it's come out?

Rochelle Shoretz: I think so. Loss of hair. The questions weren't completely clear on the background, but I guess women are calling in who are very concerned about the loss of hair.

Angela Powell: Hi, this is the other Angela. Can I answer part of that? I think it might be partially the issue of when your hair comes out especially for an African-American person and then it comes back and it comes back in a different texture usually, which is much softer. For African-American women especially, hair is both a burden and a pleasure. It's traumatic enough for your hair to come out and to be bald, because it has a lot of stigma and issues attached to it, but when it comes back and you really can't do anything with it, it's almost a noticeable sign of the fact that you've had chemotherapy. So the challenge is to find a hairdresser who knows how to deal with the change in the texture of the hair once it comes back in. I think that might be what they're asking about.

Khadijah Carter: Right. Or even just the fact that they're going to lose their hair. For me, that was a big issue and why I didn't want to get chemotherapy because of the vanity aspect of it. But when the time came, I didn't want my hair to just get thin. So I went to a barber and had her shave it for me. That was very empowering. What I did was just jazz it up with earrings and nice hats and the like.

So I just think that a lot of times we do have the vanity issue or just like you said, the stigma of cancer since you're bald. But most people didn't even think I was sick, because I tried to make myself look jazzy. I think it's a matter of empowering yourself and finding a way to just deal with the reality. Angela Pittman?

Angela Pittman: For me, the first time, of course, it was like that was my biggest thing, was like losing my hair, because I'm definitely a hair girl. My hair was long. I mean like you said, it was shedding, so I just went and had to have my brother's barber take it off. I wore scarves with nice earrings, and then I finally went out and bought myself a wig, a really nice wig.

The second time around when my hair started shedding, I just empowered

myself and took it off before it was just all coming out in my hands. It was not as big of an issue for me as I thought it was going to be.

Khadijah Carter: I think we have to be creative and just find a way to be comfortable whether it's with being bald or just losing a breast. I think this goes across the board that each individual has to find a way to cope with it. Everyone can tell you, "Oh, do this; do that," But for me it was prayer. And I know in the African-American community generally, we find a lot of solace in the church and that helped me a lot.

So aside from the negative feelings that some of us may have with the medical community, not feeling that they understand us, like my first physician, I thought she was condescending because I was young and African American. So she didn't like the fact that I was asking her questions. I was uncomfortable. So I said, "You know what? You're not on my team, so I'm going to find another physician." That alludes to what Angela mentioned. And I think it's important for us to take this into our own hands and be proactive and not passive, because again, someone mentioned that we have to live in our bodies. I don't know if that answered both questions or not.

Rochelle Shoretz: Thank you. I think it does. The final question for the evening came in from a woman who works as a Patient Health Navigator in Chicago. I think I'll broaden the question to be one that can be addressed by any of the health care professionals on the line tonight.

How can health care professionals, Patient Health Navigators, work with the diverse communities that we've had represented on the teleconference tonight to help address some of the diversity issues that we've highlighted. I'll start by answering from Sharsheret's perspective, and I mentioned this in my own talk, we've got resources right here at Sharsheret that can help familiarize health care professionals with some of the particular concerns.

So I would encourage anyone interested in learning more to access those publications by calling us or visiting us on our web site, www.sharsheret.org. But maybe one person from each of the communities can just identify a web site or a resource that health care professionals can tap into.

Anita Broccolino: Sure. I'll jump in. This is Anita from Mautner project. We have similar types of printed materials, as well as information online. Our web site address is www.mautnerproject.org. We also have a full curriculum called, "Removing the Barriers." It is CDC approved and you can get CEU credits for that. If people are interested again, go to the web site or call us at 202-332-5536 and we're happy to set up one of those trainings.

Jill Cohen: I don't think there are any web sites for health care providers to deal

with women with metastatic disease, but we do accept health care providers as members of Clubs Mets BC, which is a closed list serve available at www.acor.org. ACOR is the Association of Cancer Online Resources and it is a fabulous resource for anyone dealing with any kind of cancer.

Stacy Lewis: Great. This is Stacy again from the Young Survival Coalition. One of the things that we've done most recently that has proven to be helpful to some of the health care providers, we usually every six weeks offer a teleconference, really a networking session for young women diagnosed with advanced breast cancer. What we've done most recently was allow, with the knowledge of the calling participants, we allowed a healthcare provider to simply listen in so that she could get the benefit of hearing the issues from the women themselves, as well as hearing an experienced group moderator work with the women on the issues that they were facing currently.

So that is one resource that we have at Young Survival Coalition that may be of help, and there may be other activities that may not necessarily be direct educational activities for the health care provider, but services available to the women themselves that the health care provider may have access to, to really have a hands-on experience with servicing the community, whichever the community is.

Jenny Romero: I actually work for Ralph Lauren's Medical Director who developed the Navigation Program. So one of the things that has been very effective at our place is our Patient Navigator. I have a population where a third are not insured, a third have Medicaid and a third may be insured, but many are underinsured. Because there are a lot of social issues also on navigators, our navigators basically eliminate every barrier, whether it'd be lack of shelter, lack of insurance or underinsured.

So they've been really very, very key in our program and to this date, we have not had to turn anyone away for lack of insurance. One of the things you may want to tell your clinic or your physician is to apply for a grant. The Patient Navigation Bill was actually signed into law and there is actually money allocated for this. I think it would help a lot of people, because I really have a population where in other places they're told to come back when they have their Medicaid. I don't have a delay in treatment.

Our Navigators handle all that stuff, whether it'd be applying to Medicaid and while they're getting it, we apply directly to the patient pharmacy assistance program, so we're able to start treatment without delay. And we work with other communities. For instance, we don't have radiation oncology at our clinic, but I'm able to get patient radiation oncology because in New York City, there are city hospitals and they have to treat you. So they make up the chemo at my place, but I've worked with other institutions where they then go and get their radiation.

I think Patient Navigation Program will be very key in eliminating a lot of barriers.

Rochelle Shoretz: That completes the question and answer sessions from my part. Khadijah, I'll turn it back to you for closing remarks.

Khadijah Carter: I just want to thank everyone for their enthusiasm and questions and you've all contributed to making this teleconference a great success. We hope that you found it helpful and that your questions were answered. Again, if you have more questions or if you were not able to ask your question tonight, please send an email to info@youngsurvival.org and we will do our best to answer them. The Young Survival Coalition is here to provide you with the information you need as a young woman with breast cancer and to serve as your point of contact.

If you are registered on the Young Survival Coalition web site, and I assume that most of you are, you will continue to receive information about upcoming programs, newsletters, and announcements that affect you as a young woman. If you are not on our mailing list, please visit youngsurvival.org to register.

Sharsheret has launched the Sharsheret Forum on its web site, www.sharsheret.org. The online, moderated forum allows women facing breast cancer to post and respond to questions and concerns and is designed to accommodate the needs of women who seek privacy in connecting with others who share their diagnosis and lifestyle. Family members and caregivers also benefit from participating in the Forum by sharing strategies with other caregivers who are facing similar challenges and concerns. We welcome you to visit our new forum at www.sharsheret.org and generate important discussions like the ones presented this evening.

That concludes our program for this evening. Again, I'd like to thank our presenters, Dr. Olopade, Angela Pittman, Rebecca Sze, Kristine Tanno, Dr. Schnabel, Rochelle Shoretz, Dr. Romero, Ivis Sampayo, Anita Broccolino, Angela Powell, and Jill Cohen. We also wish to thank the collaborating organizations that supported our efforts: Sisters Network Inc., Asian and Pacific Islander Health Forum, The Mautner Projects, LatinaShare and The Ralph Lauren Center for Cancer Care and Prevention.

Rochelle Shoretz: Khadijah, I'd also like to just interject and thank you. I know how much time you and Elana Silber put into coordinating this. I can't even imagine how many details go into organizing this many speakers. Thank you very much.

Khadijah Carter: You're welcome. I'd like everyone to know that a transcript of this call will be posted on the Young Survival Coalition web site, as well as Sharsheret's web site. Finally thanks to all of you, we hope to see you in Denver

at our sixth annual conference for young women affected by breast cancer on February 24 through the 26. For more information on the conference and travel scholarships, please visit the conference web site at www.youngsurvivorsconference.org. Thank you all, stay well, and good night.

V. About Sharsheret

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

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

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

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

VI. 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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