

The Impact of the Holocaust on Breast Cancer in Jewish Families Today

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Presented By



Linking Young Jewish Women in Their Fight Against Breast Cancer

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I. Introduction

Elana Silber, Director of Operations, Sharsheret

Elana Silber: Thank you all for joining us this evening as Sharsheret presents the teleconference and webinar, The Impact of the Holocaust on Breast Cancer in Jewish Families Today.

I am Elana Silber, Director of Operations at Sharsheret, and I'm delighted to welcome you all to the call tonight. Thank you to our sponsors, the Julius and Emmy Hamburger Memorial Fund and the North Jersey Affiliate of Susan G. Komen for the Cure, for their critical support of our culturally-sensitive programming. We are pleased to welcome more than 100 of you tonight who are on the line with us. You are Jewish women and families touched by breast cancer, Jewish organizations, senior groups, Holocaust program representatives, cancer organizations and health care professionals. We appreciate your time.

Before we begin, I would like to highlight Sharsheret as an available and valuable resource for those of you participating tonight and for your family and friends. Sharsheret offers 10 national programs supporting thousands of Jewish women and families and educating community leaders and health care professionals about the unique issues of Jewish women and families facing breast cancer.

Over the last 10 years, we have responded to more than 19,000 breast cancer inquiries, involved more than 1,000 peer supporters, and presented over 200 educational programs, like this one tonight, nationwide. We offer a continuum of care for the Jewish

community. Whether you are concerned about the risk of breast and ovarian cancer in your family, diagnosed with cancer and undergoing treatment or facing issues of survivorship or recurrence, Sharsheret is here for you at every stage. We encourage you to visit our website, www.sharsheret.org, or call us to learn more about our free national programs.

In the cancer community, the word “survivor” is one commonly associated with men and women diagnosed with cancer who valiantly fight the battle for survival. The term “cancer survivor” seems to be everywhere - displayed on t-shirts, on TV and radio, in the newspaper. In the Jewish community, however, the word “survivor” has traditionally been reserved for those who survived the horrors of World War II and the Holocaust.

For the Jewish cancer survivor, the term “survivor” can be troubling and we’ve heard from many women who have difficulty embracing it, who would prefer not to be known as survivors. Tonight, we have the unique opportunity to address both groups of survivors as we explore the effects of the Holocaust on breast cancer in Jewish families today.

A recent study conducted in Israel and led by our panelist Dr. Lital Keinan-Boker, concludes that the rate of breast cancer is particularly high among Jewish women who spent the war years in Nazi-occupied Europe. The implications of this study are obviously important to Jewish families. But the results of the study extend beyond the Jewish community, with broader implications for the breast cancer community at large. What effects may diet and stress have on the incidence of breast cancer? How much of

breast cancer is shaped by our life circumstances? How much is shaped by genetics and in what ways may the two intersect? What is the intergenerational impact of breast cancer and how does breast cancer affect the sons, daughters, and the grandchildren of those who have been diagnosed with the disease? As the Jewish response to breast cancer, Sharsheret is proud to host tonight's discussion.

It is with great pleasure that I now introduce Dr. Lital Keinan-Boker who will discuss her recent study of breast cancer among Israeli Jewish Holocaust survivors. Dr. Keinan-Boker graduated from Hebrew University's School of Medicine and the School of Public Health. She holds a PhD in Epidemiology from the University of Utrecht in the Netherlands. Dr. Keinan-Boker is the Deputy Director of the Israel Center for Disease Control and a researcher and faculty member of the University of Haifa's School of Public Health.

Again, thank you Dr. Keinan-Boker, for joining us live from Israel in the middle of your night to share with us the important results of your research.

II. Recent study demonstrating a higher incidence of breast cancer among Israeli Jewish Holocaust survivors.

Lital Keinan-Boker, MD, PhD, MPH, Faculty Member of the Faculty of Social Welfare and Health Sciences, University of Haifa

Dr. Keinan-Boker: Thank you very much. Good evening. I'd like to thank Sharsheret for giving me the opportunity to present the study on cancer incidence in Israeli survivors of World War II. My presentation is based on a manuscript, which was recently published in the Journal

of the National Cancer Institute describing the master thesis of Neomi Vin-Raviv, my student and co-author.

We'll start at the beginning. The study idea was actually the result of an observation made by Dr. Barchana, the Director of the Israel National Cancer Registry. She had noticed that older European-born Jews had higher cancer rates than other ethnic groups in the Israeli population. She also noted that many of these subjects were Holocaust survivors. The question was, are these facts related?

Why would Holocaust survivors be at higher risk for cancer? They were exposed to severe conditions that may have affected their health either acutely or chronically, such as severe hunger, extreme stress, forced labor, infectious diseases, severe exposure to the elements and many others. But are these fact related to cancer? Regarding hunger, we have ample data from animal studies on the long-term impact of calorie restriction. In fact, there seem to be diets that are calorie-restricted that seem to be very helpful. Calorie-restricted animals live longer and have less chronic age-related diseases such as pericardial disease and cancer, compared to an unrestricted animal. However, in animal models, the diets may be calorie-restricted but it's life-long, not transient, and well-balanced in terms of nutrients. Not at all the situations found in humans exposed to hunger.

The problem is that we have very little data from human studies. Anorexia nervosa patients are exposed to long-term caloric restriction. Impaired bone structure and higher risk for heart disease at a later age is associated with this disorder. As for cancer, two studies so far suggested, not very convincingly, that

breast cancer may in fact be less common in anorexia nervosa patients as compared to healthy individuals. We also have data from non-Jewish World War II survivors who experienced short-term but severe hunger during the war years. There were several studies done on non-Jewish, Scandinavian, Dutch, British, and Russians who were all exposed to caloric restriction at different levels. From 1,240 calories a day in Scandinavians to 300 or less in Russians during the siege on Leningrad and for different periods of time. Even though not consistent, some of the studies suggest that breast cancer may be more common in those who more exposed.

So we have some data to support severe hunger as a risk factor for long-term morbidity, how about ecological stress and cancer? There are several biological mechanisms that could explain such a relationship, but ultimately the current scientific data does not support it. However, there are open questions. Perhaps the association is indirect. Psychological stress may lead to certain lifestyles that eventually increase cancer risks, such as smoking and alcohol consumption. Another open question is what is the role of post-traumatic stress disorder? These questions were not really investigated in the current study. We mostly looked at caloric restriction.

Based on this background, we have some hypotheses. The first hypothesis is that Jewish survivors of World War II, who were exposed to more severe caloric restrictions than the non-Jewish survivors, are at higher risk for cancer compared to non-exposed Jewish people. The second one refers to the sex and age of the exposed - the younger the age, the higher the risk.

What did we do in order to prove our hypotheses? We have designed a retrospective cohort survey. The study population consisted of two subgroups. The exposed subgroup included Jews born in Europe who lived there during World War II and who immigrated to Israel in 1945 to 1989. The assumption was that if they were in Europe during the war, they were exposed to some or all of the risk factors mentioned.

The non-exposed subgroup consisted of Jews born in Europe who immigrated to Israel up to 1945, assuming that if they were able to immigrate from Europe even in the war years, their exposure to the Holocaust horrors was minor or null. At this point, it seems important to stress that we did not reach the participants in person. The study was actually done through several databases. The definition of the study population was done through the Israeli Central Bureau of statistics database, which includes birthdates, places of birth, and immigration dates on all Israeli citizens. Thus we were able to define our study subgroups as explained earlier.

Once the study cohorts were established, we were able to link it to the National Cancer Registry database and to identify all cancer cases in each study group since 1960, the year the registry was established, through 2004, the end of the follow-up. The cancer rates in the non-exposed group served as a reference for the observed rate that should be expected in the study population. We compared the cancer rates in the exposed group to those in the non-exposed in order to find out whether they are higher, equal or lower than expected. The exposed group was in fact four-fold larger than the non-exposed group. In total, almost 1,700 cancer

patients were diagnosed in the two subgroups during the 45 years of follow-up.

What types of tumors were diagnosed? A large variety, but the most common tumor was breast cancer, then colon cancer, and then lung cancer, and prostate cancer. This is pretty much what we see in the general population. For both sexes in all birth cohorts, cancer rates in the exposed are always higher than expected and these results are unlikely to be accidental. We will now go briefly over a few types of cancer. The exposed women were at higher risk for breast cancer as compared to the non-exposed.

Interestingly, the risk was higher for those younger at exposure, that is those born in 1940 to 1945. A similar trend is seen for colon cancer for men as well as women. The exposed men had a higher risk of lung cancer compared to the non-exposed. The same is true also for lung cancer in women.

In order to assess the risk of prostate cancer, we have divided the analysis into two time periods: the one before the PSA testing in Israel, that is 1983 to 1990, and the one after it was introduced 1991 to 2004. We observed lower risk for the exposed as compared to the non-exposed in the earlier time period. We did observe the same trends in the later period when PSA was introduced into Israel.

In summary, the results indicate that exposure compared to non-exposure is associated with higher risks for all five cancers as well as specific cancer types. For breast cancer in women and colorectal cancer in both men and women, the younger the age of exposure, the higher the risk.

I would like to point some of the study limitations. First, one of the study groups, the non-exposed born in 1940 to 1945, was actually very small and limited our ability to draw conclusions in some classes, especially where specific cancer types were concerned. Second, the exposure variable was based on a proxy that is based on demographics and not on the actual personal experience of each participant. This is because we were using databases. Next, we had no data regarding individual risk factors, such as smoking habits, which could have interfered with the results. Last, we have no data on cancer diagnosed before 1960, even though this may be a minor problem, and on Jews residing outside Israel.

To conclude, we were able to support our study hypothesis that Jews exposed to World War II in Europe were at higher risk for cancer as compared to their counterparts that were not exposed to the war horrors. This was true for all cancer types and for some specific cancer types. We did observe that for certain cancer types, the younger the age of the exposure, the higher the risk. Breast cancer was one of them. Due to the study limitations, these findings warrant further investigation and the sooner the better because time is a limiting factor here. I'd like to thank you for your attention.

Elana Silber: Thank you, Dr. Keinan-Boker for the amazing statistics and information. We'll be looking forward to hearing about the case control study.

I would like to now introduce Niecee Schonberger, Sharsheret's Genetics Program Coordinator. Ms. Schonberger has provided

genetic counseling in all aspects of the field and has focused on cancer genetics for the past 10 years. She is a founding member of the National Society of Genetic Counselors and the voice on the other end of the phone when you call Sharsheret to discuss genetic counseling and genetic testing. Tonight, Ms. Schonberger will discuss the issues and concerns of Jewish women and families considering BRCA testing.

**III. The issues and concerns of Jewish women and families considering BRCA testing.
Niecee Schonberger, MS, CGC, Genetics Program Coordinator, Sharsheret**

Niecee Schonberger: Thank you, Elana. Good evening. I'll be speaking about the genetics of breast cancer and the influence of the Holocaust on issues relating to risk assessment.

Much to the surprise of many women, most breast cancer is not inherited. 90 to 95 percent of breast cancers are sporadic, the result of the interaction of mostly unknown environmental factors and the specific individual makeup of the woman. However, 5 to 10 percent of the time there may be certain indications in the personal and family history suggestive of an inherited predisposition to breast and other cancers. Therefore, it's important to become familiar with these signs, both for one's own health and the health of family members.

Genetics is a family affair and a genetic susceptibility to cancer can reach across generations, affecting not only one's health but also one's children, siblings, and beyond. However, Holocaust survivors and their children may not have that important information. Their

relatives often didn't live long enough to develop any cancer and those that did were lost before their histories could be noted.

Since both males and females can carry the genes associated with cancer, a woman can get some history from the parent who was not affected by the Holocaust. But that still leaves a large gap on the other side and no way to determine if she is at increased risk. She can opt to undergo genetic testing, but the testing itself has its own limitations, which I'll explain by discussing what the testing entails.

Inherited breast cancer is largely due to alterations in two genes: BRCA1 and BRCA2. We all have these two genes and when they function normally, they control cell growth. When one of these genes is changed or altered, this is called a mutation, the ability to control cell growth is impaired and cancer can occur. Mutations don't cause cancer; they cause a predisposition to cancer. There are over a thousand mutations known today on these two genes.

Ashkenazi Jews are more likely to carry a mutated gene than women or men in the general population. Studies have shown that two specific mutations in BRCA1 and one mutation in BRCA2 are more common in individuals of Ashkenazi Jewish descent, and that these three mutations are found in approximately 2.5 percent of Ashkenazi Jews unselected for family history. This is far greater than the estimated frequency of all mutations in the BRCA genes in the general population. This can be explained by the occurrence of these mutations in one of the many founders of Ashkenazi Jews many, many, many generations ago and is referred to as the "founder effect".

Other ethnic groups also have founder mutations that are more common in their respective populations due to the same phenomenon. Many of the challenges faced by Jewish women facing breast cancer are unique. Not only are they more likely to carry a harmful mutation, but there may be significant psycho-social challenges as well. In some Jewish families, having a genetic mutation is perceived as a taint and the diagnosis is kept secret, shutting off the support she particularly needs at this time of stress. Living in a close-knit community, as many Jews do, can be extremely supportive. But the other side of that is a lack of privacy along with the perception that the whole subject of cancer is taboo, especially when it comes to genetic testing.

She may worry about the implications of testing positive and the impact on her children, their cancer risks, and their ability to marry. There are the implications of tattooing when done as part of reconstructive surgery, as tattooing is generally prohibited under Jewish law. There's the difficulty of arranging hospital stays or treatment appointments that take place on the Sabbath or a Jewish holiday. And the issue of how to prepare for the mikvah or healing waters after surgery or during chemotherapy.

As I said earlier, your family history on both sides of your family is the key to assessing your risk for hereditary breast cancer. Multiple cases of breast and/or ovarian cancer on the same side of the family, your mother's or your father's, can indicate an increased risk as does cancer diagnosed under the age of 50. Genetic testing is available for those found to be at increased risk.

The benefit of testing is that if a mutation is identified, measures can be taken to minimize risk and hopefully diagnose cancer at an early stage when it's most treatable. The limitation is that a negative result doesn't mean that there's no risk if there's a strong family history of cancer, since there may be other genes or mutations not yet identified that this test will not detect.

Therefore, genetic counseling is an essential component to genetic testing to assess your individual risk and to review the benefits and limitations inherent in the testing process. The genetic counselor will first draw up a pedigree from the information you provide about your family. From that, the counselor will determine if testing will be useful and, if so, which particular genetic test is appropriate.

In this pedigree (referring to slide), the circles are women and the squares are the men. The 35-year-old woman indicated by the arrow wants to know if she's at increased risk to develop breast cancer. Her father's sister had breast cancer at age 41 and her paternal grandmother at age 49. The person who should actually have the test is her aunt since the results will be more definitive in an individual who's been affected by cancer. If her aunt tests positive, it would be advisable for her father to test next since he would have a 50/50 chance of either having the mutation or not having the mutation. If he does not have the mutation, then neither the woman nor his sister needs to test.

If her aunt, on the other hand, tests negative, there's no need to test anyone else. Since if there were a mutation that could be identified, her aunt would have been positive. But then the woman still has to consider herself to be at higher risk than the general

population based solely on her family history. It's been demonstrated that women with a strong family history of breast cancer that test negative are four times more likely to develop breast cancer than the average woman.

This is all very well and good, but obviously it's not always possible to obtain that all-important family history. Without the knowledge of family history in light of a negative BRCA analysis, a Jewish woman can be left without any basis for estimating her true risk. I've counseled many women who are concerned about not only about their own risks, but their children's risks as well.

If this woman had been a child of Holocaust survivors, she may not be able to trace her family beyond her parents and the pedigree would be useless for estimating her risk. She can have the genetic test, but if she tests negative, she has no more information than before she tested. Just based on the fact that Ashkenazi Jews have a 1 in 40 chance to carry a mutation, the general recommendations for her future would be to increase her surveillance by having a clinical examination of her breasts several times during the year and perhaps have an ultrasound or MRI during the six month period between her mammograms.

A negative result in an unaffected woman who has no known history is not definitive and offers no additional information other than that she doesn't have any of the known mutations. This lack of an informative family history is just another example of the impact of the Holocaust whose negative impact continues to this very day.

Elana Siber: I'd like to remind everyone on the call that you can submit your questions during the presentation. If you are accessing the webinar, please type your question into the box on the lower right hand side of your screen under the Q&A box. If you are joining us by telephone and would like to call in your question, please press *1 and an operator will assist you. Questions will be posed to the panelists during the question and answer session after the presentation. Thank you, Niecee.

I would now like to introduce Rifky Atkin to share with us the challenges she faced in tracing her family cancer history when she was diagnosed with breast cancer. Rifky is a 13-year breast cancer survivor who has served as a peer supporter and volunteer for Sharsheret since our founding. A child of Holocaust survivors, Rifky was faced with an unknown medical history upon her diagnosis, having lost all four of her grandparents in Auschwitz during the war. Rifky now lives in Edison, New Jersey with her husband Jack and is the proud mother of four children and two grandchildren. Please welcome Rifky Atkin.

**IV. The challenges I faced in tracing my family cancer history.
Rifky Atkin, Sharsheret Peer Supporter and Child of Holocaust Survivors**

Rifky Atkin: Thank you, Elana. Thirteen years ago as a Jewish woman in her thirties and mother of four children between the ages of 6 and 14, I found a lump in my breast during a routine self-exam. I had no history of breast cancer in my family that I knew of and having led what is generally considered to be a healthy lifestyle, I had no reason to doubt the doctor's assessment that it was probably

normal breast tissue. His suggestion was, "Let's watch and wait for six months and see if things change. Maybe the lump will disappear on its own." But the lump did not disappear and, in fact, it continued to grow until it was no longer just palpable, it was now obvious with the surrounding skin beginning to dimple and pucker. Alarmed, I could no longer wait out the full six months. I called my doctor demanding further tests be scheduled before the six months was out and that a biopsy - which probably should have been done in the first place - be taken at once.

In the days before the biopsy was to be done, I found myself doing constant self-exams. Largely due to my increasing anxiety, but also because I was beginning to realize I could trust no one other than myself when it came to my health. As if to justify my fears, the shape of the second barely-palpable mass began to take shape under my fingers right next to the one I already knew about. Even more alarming, I could now detect a grape-sized nodule in my armpit.

The biopsy results confirmed my fears, a 2.8 centimeter primary infiltrated ductile carcinoma, and adjacent to it, a second tumor 0.8 centimeters in size. Days later pathology of the lymph node sampled from my armpit confirmed that the cancer had already spread to five nodes.

My surgeon tried to alleviate my distress by assuring me that she would remove every bit of the tumors. But as is often the case with breast cancer, she also told me that while her surgical skills could remove the tumors she knew about, there might be circulating tumor cells elsewhere that were not known to us and that those

types of cells might lead to a recurrence months or years later. More importantly, she pointed out that as an Ashkenazi Jewish woman, it was crucial to know my family's possible history of breast cancer since this too might aid in predicting the chances of recurrence. Knowing those risks would dictate what kind of treatment plan would be devised for me.

"Do you have a history of breast cancer in your family?" she asked. I was unable to answer her question, finally stammering, "I don't know and I'll never know." You see, I am a child of Holocaust survivors. Both my parents survived Auschwitz as teenagers. But their parents, all four of my grandparents, were killed in the gas chambers and with them was lost any knowledge of illness that may have run in the family. Not only that, having lived only until their early forties, there was no way of knowing whether breast cancer was to be in their fate had they lived longer.

My mother and her older sister, the two oldest children in their family, were the only survivors from their family of five children. Of the three children in my father's family, my father and his older brother and sister were all lucky enough to survive. None of them had breast cancer or any type of cancer that may sometimes appear in families who have inherited the BRCA1 or BRCA2 gene mutations that are found in, what I think is, approximately 15 percent of breast cancers that are diagnosed in Ashkenazi Jewish women. But not being able to know your medical history beyond one generation above me still left a lot of questions opened and underscored the importance of having that knowledge to help guide me in deciding the right treatment plan.

With no knowledge of my family history and chances of recurrence, I decided to turn to the most aggressive treatment plan available at that time, which was 1997. After surgery to remove the tumors and months of harsh chemotherapy, I was admitted to Hackensack Hospital in New Jersey for two weeks to undergo an autologous stem cell transplant together with high-dose chemotherapy. After recovering from that ordeal, there was six weeks of radiation to my chest and neck area. Finally, I began hormonal anti-estrogen treatment with Tamoxifen. That lasted five years and then we switched to the aromatase inhibitor Femara, which I continue to take to this day.

About five years after my diagnosis, I was contacted by a geneticist at Hackensack Hospital offering me an opportunity to join a study of Ashkenazi Jewish breast cancer survivors. As part of the study, each participant would be tested for the known breast cancer gene mutations, BRCA1 and BRCA2. After some initial hesitation, I decided to join. Being able to discover a part of my genetic makeup gave me a sense of empowerment, enabling me to make decisions about my own ongoing treatment. For example, considering whether or not I should undergo an oophorectomy, or surgical removal of the ovaries. More important, by knowing the results of the blood test, I could now pass on to my daughters and to my identical twin sister some knowledge of the family history that had been erased when my grandparents perished in the Holocaust. Looking back over the past 13 years, I am grateful that with God's help and with the treatment plan that was chosen for me, I am here today to tell my story. Thank you.

Elana Silber: Thank you, Rifky, for those inspiring remarks.

V. Question and Answer Session
Elana Silber, Director of Operations, Sharsheret

Elana Silber: It's now time for questions and answers. We will begin with questions that have already been submitted.

Dr. Keinan-Boker, this question is for you. This is a child of Holocaust survivors and she says that her mother and two of her sisters all survived the Holocaust. One sister died in the 1960s of cancer, but we are not aware of what kind of cancer. Her other sister died of colon cancer in 1990. The caller's mother died of non-Hodgkin's lymphoma in 1999. Her question is did your study research families, sisters, and did you see this kind of situation? Is this typical that all three sisters would be diagnosed and to have all different cancers as opposed to just breast and colon cancers that seem highly identified in your study?

Dr. Keinan-Boker: I cannot say that because, as I mentioned in my presentation, we didn't have personal data or personal details on the people who were participating in our study. It was a list of names that was linked to the database of the National Cancer Registry, so I cannot know whether between our cancer cases there were brothers and sisters or other family members. It makes sense to me that if we found higher cancer risk in Holocaust survivors, then it may be extended to all family members. But this is just an assumption and I cannot say that this is true.

What we did recommend in the conclusions from our study is that sons and daughters of Holocaust survivors and also Holocaust

survivors themselves should go for regular medical examinations just to check and see whether they are at higher risk for cancer. If you're reminded about your yearly mammogram, go and do it.

Elana Silber: There was another question. I know you mentioned briefly additional research or follow-up to this study. Is there any more information you can share with us about what's coming down the pike now?

Dr. Keinan-Boker: Yes, because we were very interested in this issue of breast cancer, we've conducted another case control study based on Holocaust survivors only, some of them with breast cancer and some of them as controls without breast cancer. We were asking what could be the explanation for the higher risk in these women. They were all exposed to the Holocaust but some of them were more exposed, some of them were less exposed. This time we did collect personal data and personal information. We did ask them about themselves about their whereabouts, about their lifestyle, about all kinds of things, as much as possible of course. We could not ask them for family history, as you can understand. The data collection was actually finished a month ago and now we're looking at the results.

Elana Silber: Thank you. I have a question for Niecee. Niecee, how can families of Holocaust survivors be helped by Sharsheret's Genetics for Life program? What happens when a family member calls Sharsheret? What could we do for them?

Niecee Schonberger: We can get as much family history as possible, sometimes there is some. But if there was none, then we would talk. As I said

earlier, we would talk about the genetic testing because I think it's important to either rule out or rule in a mutation which changes the way the woman would be followed and also indicates risk for other family members. The first thing I always recommend is sitting down with a genetic counselor and going through all the details of genetic testing, the benefits of the genetic testing as well as the limitations that I spoke about earlier.

A good way to identify a genetic counselor is through the website for the National Society of Genetic Counselors, www.nsgc.org, which would identify somebody in your area that you could talk to. I would be happy to discuss in detail over the phone as much about the genetic testing as I possibly can.

Elana Silber: Thank you. This is for Dr. Keinan-Boker. A caller wants to know, does the stress of the Holocaust survivors cause an increase in risk for the children of survivors? Does that low calorie intake of the parent or their psychological stress have an impact? Are there any studies on the children of Holocaust survivors themselves?

Dr. Keinan-Boker: That's a very interesting question. The Dutch people did such research on the children of those exposed to the Dutch Hunger during the war and they do have very interesting findings. Offspring of those exposed are actually at higher risk for certain diseases, including cancer. We do not have a study on Holocaust survivors yet, but we do plan to make such a study in Israel.

Elana Silber: We've actually gotten several questions about the children of Holocaust survivors. I have a question now for Niecee. We've heard that people who carry a BRCA mutation may never develop

cancer. Is it fair to assume that living through the Holocaust triggered BRCA genes that may otherwise have remained dormant?

Niecee Schonberger: We do know that people who carry the mutation may never develop cancer. It's not a 100 percent risk of cancer. It's a high risk, like up to 85 percent, but it's not 100 percent. Therefore, there must be other factors, environmental, other genetic markers that might impact upon whether the mutation will express itself. Whether the stress and the caloric deprivation of the Holocaust could be one of those factors, it's certainly plausible. Do you agree Dr. Keinan-Boker?

Dr. Keinan-Boker: Actually, this is one of the explanations we did offer in our discussion in this manuscript. I think it's very possible. I just would like to mention that in our study, we were less worried about the possible effect of BRCA1 and BRCA2 because both of our populations, the exposed and unexposed, were of European origin. I'm not saying Ashkenazi because you know that not all European origin Jews are Ashkenazi, but often were European origin.

Elana Silber: This question is for Rifky. A caller wants to know, do you have daughters and what do you tell your daughters about family history?

Rifky Atkin: I think the rule of thumb for breast cancer survivors and their daughters is for the daughters to be tested 10 years before the onset of their mother's breast cancer. So the instructions for my daughters - and they know this and they're both in their early 20s - is that when they reach age 28, which is 10 years before I was

diagnosed, they should go for mammograms. That's irrespective of the results of the gene test because, like Ms. Schonberger said, even if a gene test is negative, that's the known gene mutations. We just have to be vigilant and I certainly don't want, God forbid, ever a repeat of the way that I felt that it wasn't taken seriously when I first found the lump. I want them to be vigilant. That's the message that I try to convey to them.

Elana Silber: Dr. Keinan-Boker, a lot of participants were wondering if there is any United States-based research that we could get involved with. You mentioned that time is important. Is there something we can do in the United States to further the research?

Dr. Keinan-Boker: We did look for some sources in the United States and couldn't find any. I think it's important. It's important to repeat this study and see whether the results are the same in American Jews. I can only say that my PhD student, Neomi Vin-Raviv, is actually going on a post-doc in the United States and would be very happy to conduct such a study provided we have the resources for it.

Elana Silber: This is a general question. A woman on the call is from a family of Holocaust survivors. She'd like to speak to other Holocaust survivor families that have cancer diagnoses. She wants to know if she can call Sharsheret and connect with others through the peer support program.

I'll take that question and just let you know that Sharsheret maintains a large database. We have over 1,000 women in the program with many, many details of their diagnosis, of their family history, of their issues and concerns. We certainly can put you in

touch with other families or other women who are in your situation who are Holocaust survivors. I encourage everyone to share their experience with Sharsheret; we'd be happy to speak with you and add you to our large database so that you can help other people and share your experience with them.

This is a genetics question for Niecee. This woman was diagnosed at age 42 and she has a family history of breast cancer. Her grandmother and her aunt were diagnosed and she has a niece who is 30-years old now. She wants to know, what are the niece's chances of being diagnosed with breast cancer before the age of 45? What are her risks? Niecee?

Niecee Schonberger: If there is a known mutation in the family, then the niece should be tested for that mutation. If there is no known mutation in the family and it's just a strong family history, then the niece should start her surveillance at a young age, start having her mammograms at an earlier age, start going to her doctors for clinical exams on a regular basis several times during the year. Without knowing the genetic mutation that may be in the family, there's no way to quantitate her risk. But certainly she should increase her surveillance and be particularly alert to any signs or symptoms, examine herself on a regular basis, all the recommendations for early detection. Because that's the key, early detection means early treatment and a good prognosis.

Elana Silber: If there are any follow-up questions, Niecee is available and can be reached at Sharsheret if you want to go into more detail with your family history.

Dr. Keinan-Boker, someone's asking, do you know the number of Holocaust survivors in the United States compared to the number of Holocaust survivors in Israel? Is that a number that you came across during your research?

Dr. Keinan-Boker: I did, but I'll have to refer to my manuscript in order to remember. I can tell you now that in Israel we now have around a quarter of a million, maybe 230,000 Holocaust survivors. I know that the United States is the second largest place with Holocaust survivors, so it could be a little bit less than that.

Elana Silber: Here's a question about genetics. Niecee, you talked about testing for BRCA1 and BRCA2. Is that the only test that's out there? Are there any other markers that people can test for?

Niecee Schonberger: That's a very interesting question and I didn't touch on that. Certainly most of inherited breast cancer is due to a mutation in BRCA1 and BRCA2, but there are other genes that are associated with other cancers. With BRCA1 and BRCA2, you have breast and ovarian cancer. There's another gene for a syndrome called Lynch syndrome that's associated with colon cancer. So if there's a lot of the colon cancer plus other cancers, plus breast cancer, you might think of testing for the Lynch syndrome mutations.

Then there are other genes also associated with other groups of non-random associations of cancers. Again, that's why it's important to get as much family history as possible. Because if it's not just breast and ovarian, it may indicate that there's a different gene operating in the family.

Elana Silber: This is a question for Rifky. As a child of Holocaust survivors, did you ever struggle with calling yourself a breast cancer survivor?

Rifky Atkin: That's very interesting, because I actually never really associated that conflict until I heard about it tonight. I have always differentiated the word survivor and I always spell it with a capital "S". Survivor to me means Holocaust survivor, but I always preceded that with breast cancer survivor. I don't call myself a survivor. That's my mother or my father. I'm a breast cancer survivor. So I think the answer to your question is I don't confuse the two, but I differentiate myself from just using the one word, Survivor.

Elana Silber: The question came in, is there any information out there about estrogen receptor or progesterone receptor incidence in Jewish women as opposed to the general population?

Dr. Keinan-Boker: As far as I know, usually in women it's more or less as expected in the general population in other countries, but I cannot tell regarding Ashkenazi women.

Elana Silber: Another question came in for Niecee. There's a woman who wants to know more about the connection between a woman with breast cancer who has a father who has prostate cancer. She's heard of connections. Are they connected in any way?

Niecee Schonberger: With the mutation, there seems to be a slight association with an increased risk of prostate cancer but usually at a younger age. You have to remember that prostate cancer is very common in older

men. So if you see it in a family, it doesn't ring any bells. But if you see prostate cancer at the age of 50 or 55, that's young, so there probably is some kind of an association but it's not as strong an association as it is for breast and ovarian cancer.

VI. Teleconference Conclusion Closing Remarks

Elana Silber: Thank you. We can continue this discussion directly on our blog. Sharsheret's blog can be accessed at www.sharsheret.blogspot.com. Please feel free to post your comments, stories, and experiences on our blog and share it with all of our supporters and all of our contacts, even those who are not even on the call tonight. If you have any additional questions that you would like to pose for the presenters, please feel free to e-mail us at info@sharsheret.org and we will forward your question to the appropriate panelist.

I'd like to thank Dr. Keinan-Boker, Niecee Schonberger, and Rifky Atkin for joining us tonight to explore the impact the Holocaust has on breast cancer and Jewish families today. A transcript and audio taping of this presentation will be available on Sharsheret's website, www.sharsheret.org, and you will also be able to access it on our blog, www.sharshseret.blogspot.com, in the next couple of weeks.

We also encourage you to visit our website to read more about our upcoming events, including our 10th anniversary celebration in October. You can watch recent TV coverage of Sharsheret and learn more about our 10 national programs supporting thousands of

Jewish women and families facing breast cancer across the country. Thank you all and have a good night.

VIII. Speaker Bios

Rifky Atkin is a 13-year breast cancer survivor and has served as a peer supporter and volunteer for Sharsheret since its founding in 2001. A child of Holocaust survivors, she was faced with an unknown medical history upon her diagnosis, having lost all four of her grandparents in Auschwitz. Rifky is a Software Quality Assurance Manager at New York Life Insurance Company, and is the mother of four children and two grandchildren. She and her husband, Jack, reside in Edison, NJ.

Lital Keinan-Boker, MD, PhD, MPH is a co-author of “Cancer Incidence in Israeli Jewish Survivors of World War II”, <http://jnci.oxfordjournals.org/cgi/content/abstract/101/21/1489>. The article, published in 2009, is based on the research study of Israeli Jews of European origin, many of them exposed to severe famine and stress during World War II, who seem to have high incidence rates of all cancers. Dr. Keinan-Boker graduated from Hebrew University’s School of Medicine and the School of Public Health. She holds a PhD degree in Epidemiology from the University of Utrecht in the Netherlands. Dr. Keinan-Boker is the Deputy Director of the Israel Center for Disease Control. She is also a researcher and faculty member of University of Haifa’s School of Public Health.

Niecee Singer Schonberger, MS, CGC is Sharsheret’s Genetics Program Coordinator. Ms. Schonberger graduated from Sarah Lawrence College with a Master of Science in Human Genetics. She has provided genetic counseling in all aspects of genetics, and for the past 10 years, has focused on cancer genetics. She is a founding member of the National Society of Genetic Counselors and a past president of the Human Genetics Association of New Jersey. Ms. Schonberger provides supportive

counseling, information, and resources regarding hereditary breast cancer to women diagnosed with and at high risk of developing breast cancer.

VIII. About Sharsheret

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

Since Sharsheret’s founding in 2001, we have responded to more than 19,000 breast cancer inquiries, involved more than 1,000 peer supporters, and presented over 200 educational programs nationwide. Sharsheret now offers a continuum of care for the Jewish community – addressing the needs of those who are concerned about the risk of breast cancer in their family, those who have been diagnosed with the disease and are undergoing treatment, and those who face issues of survivorship or recurrence.

Sharsheret has developed 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;
- *Sharsheret Supports*, developing local support groups and programs;

- *Family Focus*, providing resources and support for caregivers and family members.

Education and Outreach Programs

- *Health Care Symposia*, on issues unique to younger women facing breast cancer;
- *Sharsheret on Campus*, outreach to students on campus;
- *Facing Breast Cancer as a Jewish Woman*, an educational resource booklet series.

For more information about Sharsheret, please visit www.sharsheret.org or call (866) 474-2774.

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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