You, Your Family, and Your Jewish Cancer Genes: Everything You Need to Know

National Webinar Transcript

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SHARSHERET®
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Table of Contents:

I. Introduction

Bonnie Beckoff: Good evening. I wanted to welcome all of you to Sharsheret's national webinar, “You, Your Family, and Your Jewish Cancer Genes: Everything You Need to Know.” We are excited that so many of you have joined us tonight and that many states across the country are represented this evening.

My name is Bonnie Beckoff and I am the Senior Support Program Coordinator for Sharsheret. I'm happy to be here moderating tonight's webinar. Sharsheret supports young Jewish women and families facing breast and ovarian cancer at every stage. We help you connect to our community, whatever your personal background, stage of life, genetic risk, diagnosis, or treatment.

We would like to thank Astrazeneca, Myriad, The Centers for Disease Control and Prevention, The Florence & Laurence Spungen Family Foundation, The Marcus Foundation, and The Siegmund and Edith Blumenthal Memorial Fund for their ongoing support and sponsoring tonight’s program.

As many of you know, 1 in 500 individuals in the general population carries the BRCA mutation. For those individuals of Ashkenazi Jewish decent, that number increases to 1 in 40. This means that Ashkenazi Jews are 10 times more likely to carry the BRCA mutation, resulting in as high as 80% lifetime risk of being diagnosed with breast cancer, and as high as 44% lifetime risk of being diagnosed with ovarian cancer. Sharsheret is often posed with the questions of how to communicate with family members about a BRCA diagnosis. When should one tell a family member? What are the risks and why is it important to know one’s family history and genetic history. Communication with one’s family members can vary within one’s family structure and family dynamics. Often, there are families who are private about their family history due to cultural stigmas or generational relevance. Often at Sharsheret we are posed with these confusing and conflicting questions about genetics. Tonight's webinar will answer your most commonly asked questions.

One more thing before I introduce our speaker for the evening. You can ask questions throughout the webinar by typing in the question box on your dashboard, on the right side of the screen. Please keep your questions broad in nature so that everyone on the call can benefit from

the discussion. We will try to get to as many questions as we can after the presentation. Those of you, who are not joining us via computer, please know that you can call Sharsheret at any time with your questions and we will be happy to discuss them with you.

It is now my pleasure to introduce our speaker, Ms. Peggy Cottrell. Peggy is a graduate of the Sarah Lawrence College Master of Science and Genetic Counseling program. At Sharsheret, as our Genetics Program Coordinator, Peggy consults with women and families and answers individual questions about their family histories, BRCA mutations, and personal risks of hereditary breast and ovarian cancer, and contributes to the development and implementation of Sharsheret's hereditary cancer resources and programs. Peggy is also a certified genetic counselor in the regional cancer center at our partner, Holy Name Medical Center.

Peggy, the floor is yours.

II. Everything You Need to Know About Genetics

Peggy Cottrell: Bonnie-thank you so much for that wonderful introduction and we'll get started here. So I'm repeating from what Bonnie said that 1 in 40 Jews carry a mutation in BRCA1 or BRCA2. And we would like to think that every time there's an inherited mutation and a family, we're going to see lots of family history of cancer and that it's going to be very easy to identify that this family is at high risk; but that's not the case. Sometimes people test positive and the family history is not straight forward.

So why is that the case? So there are some common issues that make it difficult to see what's going on in a family tree. One thing that's unique to Ashkenazim is the Holocaust, and sometimes there are family members who have been lost and families are small and so we can't go all the way back and see what grandparents or great grandparents or uncles might have died from had that they not been killed prematurely. Sometimes families are naturally small and people may have few or no siblings few or no aunts, and so a small family gives us less information. Family members can be out of touch with each other and we see this happen a lot. Someone might say to me look, you know, I know I have cousins, but I really don't know what's going on with them. Sometimes we see families where there is a preponderance of men, and it's not that men don't get cancer when they are carriers of mutations in BRCA1 and 2, but they're much less likely to get cancer than female family members, and sometimes people are just not really thinking about the fact that they can inherit a BRCA1 or BRCA2 mutation from their paternal side.

So when we look at a family tree, we're looking at the branches from both sides- from the men and from the women to see what kind of cancer is there.

So current testing guidelines have broadened and we talked about this a little bit in last year's webinar that there are updated guidelines that are trying to be more inclusive so that we can test broader numbers of people and get that testing covered by insurance. Any Ashkenazi Jewish woman with breast cancer at any age meets guidelines. So even if you were diagnosed and you were 80; if you have Jewish ancestry that's enough to make us suspicious. And so that will be covered for any person Jewish or non-Jewish, with ovarian cancer, pancreatic cancer, metastatic, prostate, or male breast cancer meets guidelines for testing.

Any person who doesn't have cancer, but they has a first or second degree relative and I'll explain what that means- a first-degree relative means somebody who's connected to you on the family tree with just one step. So parents, children, siblings, are first-degree relatives. Grandparents, aunts, and uncles, nieces and nephews, those are second-degree relatives. And so those people with first or second degree relatives as mentioned above will meet guidelines for testing. And then there are a whole lot of ways that combinations of cancers can add up to coverage and then finally, recently the American Society of Breast Surgeons came out with a recommendation that all women with breast cancer should be tested. Now most women with breast cancer are not going to have a positive result. But the American Society of Breast Surgeons doesn't want to miss people who test positive. And one thing we've learned is that a good way to identify people, who need to be tested, is for us to test the people with cancer and then very aggressively test the relatives of anyone who test positive. And that can be an important thing for finding people who will test positive.

So those are the guidelines. Now, there are other gene, beyond BRCA 1 and 2 that can predispose to cancer. Nowadays, most of the time, when someone gets a cancer genetic test, their test is going to be a panel and that panel may include anywhere from a dozen to as many as even 80 genes that are associated with cancer. Now many of those genes are associated with more obscure kinds of cancer that are pretty rare and we don't typically see so I'm going to talk just briefly about some of the other genes that we may look at.

So there are some rare but high-risk breast cancer genes that we look at PALB2 is not so rare but causes a pattern of breast and pancreatic cancer, CDH1 causes a pattern of stomach and breast cancer, PTEN can cause a number of different kinds of cancer of the GI tract and of the uterus as well as breast cancer, STK11 causes a pattern of breast and GI cancers, and TP53 can cause young breast and other rare cancers; even in very young people, even in children or teenagers. Thankfully, these

genes cause a very high-risk but they're really for the most part pretty rare and we don't see them that often.

Then there are moderate risk genes for breast cancer. And these are more common than the rare high-risk ones and they include genes like CHEK2, ATM, BARD1, NF1, and RAD50. These genes may approximately double or triple the average woman's risk for breast cancer. So we're talking about instead of having a 10-12% chance, women who carry one of these would have somewhere around a 20-30%, and again it's going to be variable depending on which one we find. And then there can be other kinds of cancers that are associated with these genes as well. So with CHEK2- maybe colon and prostate cancer, with ATM maybe pancreatic cancer; and so those are genes that are often on panels. There are also moderate risk ovarian cancer genes. There are genes that predispose to something called Lynch Syndrome, which is a pattern that mainly includes endometrial cancer, but can also include a moderate risk of ovarian cancer. I won't read through the names of those five genes, but those are the genes that cause Lynch Syndrome and then a couple of other genes like BRIP1, RAD51C, RAD51D, and STK1, that we mentioned earlier. And then there are a lot of other genes that are on the panels that are typically done and they can predispose to melanoma, colon cancer, stomach cancer, other GI cancers, pancreatic cancer, uterine cancer, and other cancers.

Now anybody Jewish could carry any one of these genes, but unlike BRCA1 and 2, we don't see that Jewish women have such a high risk. So with BRCA1 and 2, these are particularly of concern for Ashkenazi Jewish women, because they are so much more common than in the general population. That is not the case with any of these other genes that we look at. Now it is possible that there are people out there who have more questions, maybe you've tested positive for one of these genes and would like some more detail. I'm not going to spend any more time here tonight, but certainly give us a call and you can set up an appointment. I'd be happy to go into more detail if you have questions.

So why would people even get tested? How is it beneficial being able to look into the future and know that something might happen, and if that was the case, we might not really be so compelled. But there are unique medical management options that people can consider, that can significantly reduce their risk of dying from cancer; and research supports the fact that genetic testing saves lives. We don't always know for sure whose life we have saved, but we are sure from the data that we are saving lives.

Now, everybody tends to think of the big things that can be done like prophylactic surgery or risk-reducing surgery as we sometimes call it, but even enhanced screening is helpful. So the ability to do a breast MRI once a year makes a significant difference in terms of survival, and that's why it's so important for women to know if they test positive because it isn't enough if your result is positive to just get your mammogram and

perhaps a sonogram every year. Research really shows that the MRI is an important piece of being sure that people live a long and healthy life.

So Cascade testing is the name of what we call the test when someone in a family tests positive, and then we want to test their relatives. And the idea of it is like a waterfall flowing through the family, and as it flows through the family, we have the opportunity to let people know and give them the opportunity to be tested; and here is where communication is really critical. It can be very difficult to talk about these issues with family members and as hard as it is to talk about it with people you're close to like your parents or your siblings, it can be even more difficult to try to talk about it with people who you are not really in touch with like more distant aunts, uncles, and cousins. But again if we're going to get the message out there, those are really important people to communicate with because you have the opportunity to possibly save the life of these relatives. I hate to be dramatic, but I think it's really important that we all think about the fact that it's not that often in our lives that we have the opportunity to save somebody's life. And this may be one of those opportunities.

So who exactly should be contacted once someone has a positive result? The first thing I want to mention is that both men and women are important to contact. Now I said before that women are more likely to get cancer than men if they are carriers of a BRCA1 or BRCA2 mutation, but men can also get cancer. They can get prostate cancer, pancreatic cancer, and breast cancer; and men can just as easily as women past this mutation on to their children. So it's really super important for men to be aware as well as women of whether the result is positive.

So if I'm talking to someone who's tested positive, when I get to this point in the discussion, we generally pull out the family tree and we're going to take a look at all of the close relatives and talk about what the chances are that any of those people would test positive. Now, one of the first things you want to figure out is which side of the family needs to be contacted. Most of us, most of the time, this is coming down on one side of the family and not the other side, but sometimes even though there might be clues that seemed to make it obvious that it's one side compared to the other, it can be really difficult to tell. So one of the first things that could be important in cascade testing, is to test the parents of the person who's tested positive, if they are available to be tested, and then if someone's result is negative, let's say the mom's result is negative and it's coming from the dad's side; now you don't have to talk to all of the relatives on the moms side and that can make the job easier.

And then you're going to look at the dad’s side of the tree, and anybody who's connected by blood with you, out as many generations as there could be, needs to be contacted. And again, I'm going to remind you may be able to save the lives of these people. So we really want you to talk to your aunt's, your uncle's, your cousin's, your great aunts, to try to get that message out there.

Sometimes what I recommend people do, is call the people you're close to. Like let's say you have 10 cousins and there are two of them that you

know pretty well and the rest of them you don't know so well, so call the ones you know, and perhaps those people can help you to pass the information along to other cousins that they are more in touch with. You can consider an email to those that it's hard to speak with. Now I'll caution you it may not be best to write an email that says, “Hi, I've just tested positive. There's something inherited-it's BRCA1 and you're going to get breast cancer.” You want to start with something a little bit gentler. So you might consider something like, “I recently had genetic testing done and something was identified, and the genetic counselor recommended that I talked to everyone in the family. So I'd like to figure out a time to speak with you or email me back if you would just like me to send you the information. So that you give people the opportunity to accept or perhaps not accept the information. Sometimes people write a letter and this can seem kind of cold, but for people that it's really difficult to speak to sometimes this is the best option. And a couple years ago, I had a young woman who called and made an appointment, not through Sharsheret, but at Holy Name, where I work, and she had gotten a letter. She was estranged from her mother. She hadn't spoken to her in about 15 years, but she got a letter from her mother that her mother had tested positive and wanted her to know now. She was very angry about getting this letter from her mother and even after we did the consultation, we did her genetic testing, and she ended up testing positive, she was still really angry and I had to really remind her that her mother had sent her this letter now, obviously it was a long history there and there was a lot of anger, but her mother sent her this information because she really cares about her and wanted her to have this information and again may have given her the opportunity to save her life.

So what are some of the stumbling blocks to communication? So for some people it's just very hard to admit a genetic mutation. There can be issues with guilt-the thought that you might have passed this on to people that you love, your children or your grandchildren, and that can be very difficult. There are privacy issues. Sometimes people find out they've tested positive because they have cancer and they didn't want everybody to know about the cancer. Sometimes there's a stigma, the idea that something inherited means there's a defect in you and these can be difficult to overcome. Sometimes for people who carry mutations who are older, there is an issue with legacy and the older people get the more their self-worth is about not so much what's happening to them, but what's happening to their children and their grandchildren. And again the thought that they might have passed something unwittingly obviously, but nonetheless it becomes very painful to know that you've passed something like this in a family. Some family members are not going to want to know about this and so sometimes people will say, you know a parent might say to a child- I had this genetic testing done, and the child will say- I don't want to know about it or a sibling will say I don't want to know about it, I’m not interested in finding out that information. Family dysfunction and estrangement- that was the first story I talked about and I'll tell you a second story where I had a woman who came in for testing. She really didn't even meet guidelines, but she had Jewish

ancestry and breast cancer at an older age. I was pretty sure her result was going to be negative and she ended up testing positive and it was surprising because there was no one else in the family who had had cancer. So I gave her my instructions to call up her family members, and when she called her cousins lo and behold she found out that they had both had cancer, one and had breast cancer and the other one had ovarian cancer. They knew about the inherited mutation, and they had just not been able to call her. So again, I can't emphasize too much, sometimes the story could really be that if people had spoken up, there might have been an opportunity to prevent the diagnosis of cancer. And again, it's really important to communicate this information.

So now I'm going to move to a different area which is talking to children and this can be a particularly more difficult, especially if the child/children are young. So how should you approach this? So I have to start out by saying that every family is different and there really isn't any rule about how or when to tell children about the family mutation. Now, I think all of us could agree that a five-year-old is way too young and that an 18 year old is probably old enough, but somewhere in between, what brings a child to be able to handle the information of knowing about the inherited mutation. So I generally tell people that it is often beneficial to wait to tell children about the inherited mutation until they are adults. Sometimes that's because it can be pressure on kids to want to know and want to be tested. Once they know they have that 50/50 chance kids sometimes don't understand that this is not something that they really have to worry about, as this is something that really only affects them once they are an adult, and obviously once children are old enough either to get married or to begin screening that's a time when you really have to pull yourself together and figure out how to tell your children about this. And again, I'll point out that if you have used a genetic counselor at some time and have someone to call or if you want to call us at Sharsheret, we can help give you some pointers about family communication that can be beneficial. Now, there's no magic trick that makes this an easy thing to talk about and we have a booklet that I'm going to reference for talking to your children about your cancer gene and there are no magic formulas in that booklet, but it points out a lot of really good ideas for how to communicate that information.

Now I will say that even though you might tell children who are under 18, about a mutation, it is generally very rarely recommended that children be actually genetically tested until they're adults and that's because there really is no benefit for a child to know their genetic result when they're still a child; because especially there are some rare inherited cancers where children can be affected in that changes our advice. But if we're talking about BRCA1 or 2, we really want children to be adults and their right to decide how and when to be tested should be preserved and respected.

So this is our booklet, “How Do I Tell My Children about My Cancer Gene? And so I'm just going to reference a couple of the points within the booklet that can help guide you about how to talk to your children. So the first thing that's really important is to take time to process your own

results. Sometimes I talk to women very close to when they've tested positive and they feel that they must immediately go and tell their children and maybe it's even adult children that it has to be something that they do right away. And generally that's not the case. This is something that you can take the time to feel better about your own mutation and what it means for yourself and sometimes taking a couple months to get used to the idea that you carry a BRCA1 or 2 mutation, and what your decisions about what you're going to do about that, can give you a lot of maturity and comfort when you have to share it with your children. If you're still in a state of panic and you don't know exactly how you want to deal with this yet, it's going to be difficult for you to not pass that panic along to your children. You need to consider obviously the age and the life stage of each family member. I just spoke to someone recently who told me- listen, you know, I know my oldest child probably is ready to know but my youngest child is not ready to know and I know my children cannot keep secrets from each other. And so this can also complicate the decision-making process and how you decide you want to find the right time and the right setting.

So at a time when there's time and people are relaxed, when the family is all sitting together. You know your own families communication style and that's not something we can tell you but we want you to follow along with what makes your family comfortable in having these kinds of discussions. You can break these challenging tasks into small manageable pieces. So you can start with a small amount of information and then gradually increase the amount of information that you share. And sometimes I recommend to people when they are teaching their children, even when they're very young we teach our children by taking them to the doctor and telling them about how we go to the doctor that going to the doctor and getting checkups and eating healthy; that these are all important parts of taking care of ourselves. And that's the first important message that we want to share with our children in terms of keeping them healthy. And then you might eventually say, you know, I go twice a year to get checkups for breast cancer because we have breast cancer in our family. Now that's not pointing out that there's something inherited but it's the first step in that direction. So now the child these oh mom goes twice a year and she's taking good care of herself and she's keeping herself healthy. And then eventually taking it to the final step of saying okay, there's something inherited in our family that's causing this cancer, and I've inherited it and it's possible that you might have inherited.

Avoid making it a catastrophe and incorporate the positive things that can be done and the empowering health messages that are there, that there are things you can do. Simple things like eating a healthy diet, not drinking, and not smoking, go a long way to reduce some of the risk of breast cancer. And then you're going to gauge the response of your family members or children; see how they're adjusting to this new information. And then over time you're going to reinforce the support and continue the conversation as children might eventually be ready to actually consider testing themselves.

So what's next? So what we at Sharsheret want you all to know that you're not alone. We are here to help you through all of these processes. You can contact me by calling the Sharsheret office. I'm not here all the time, but you can set up an appointment to have a half an hour to talk to me. And in that situation, I can really talk to you specifically about the unique factors of your family, your cancer, of your inherited mutation, and help you figure out the best path way to take share. Sharsheret doesn't offer any genetic testing, but all of the conversations that we have our confidential, individualized, and free and we have lots of materials that we can send to you our booklet about talking to your children, our booklet your Jewish genes, and lots of other information as well that can help guide you as you head down this pathway.

So again our Genetics for Life program, that includes me as a genetic counselor. You can speak one-on-one with me. We also provide free family conference calls. So if you feel like you want to have somebody to negotiate between you and a family member and help you explain what the issues are. We can set up a conference call between you and a family. And again our booklets have a wealth of information that can provide you with the knowledge that you may need to make it easier to share this and of course we are always happy to talk to your family members. So if you talk to someone and they're like, oh my goodness, I what have you just told me and what do I do next? You can tell them to be in touch with us and we'll be happy to help them out.

Bonnie Beckoff: Thank you, Peggy. That was amazing and super informative. We really appreciate you sharing all that wonderful information.

III. Personal Story

Bonnie Beckoff: It is now my pleasure to introduce Debbi Spungen. Debbi is a carrier of the BRCA gene mutation and involved in the education of genetic testing. She has also been the family caregiver for her parents and understands the need for support in this field. She also serves on the Board of Trustees for her family's foundation, The Florence and Lawrence Spungen Family Foundation, whose mission is to improve the quality of life of individuals and families facing health challenges, and to address issues that particularly affect the Jewish community. Not only do we thank the Florence and Lawrence Spungen Family Foundation for being a part of tonight's webinar, but for their constant support of all we do at at Sharsheret. So without any further ado, I would like to ask Debbi to share her personal story about her family history and navigating her genetic risk.

Debbi Spungen: So thank you so much for all of your information. I wish I had the all that information when I went through it. In 2006, I was tested because my mother had ovarian cancer. So my whole family, I have a three siblings and we were all tested. It was almost like a little group family fun thing.

You know, we all got tested and three out of four of us, were positive for the mutation.

I was also a caregiver of my mother who had ovarian because of the BRCA mutation. I did everything you guys told me to do, what all the doctors said at that time. I did a lumpectomy and then I did the oophorectomy. And I had three out of four doctors said if we if you don't do the mastectomy, we won't see you. So of course, I went to the doctor that said we won't do it; and far so good. I get a test every six months and it's all good. With regard to my family, I am I'm the only female of four out of three of us. I was the only female that had the mutation, so I was the only one who had to do anything about it. So it was almost minimized in many ways.

And I had no support at that time. So that's just that's my experience at that time. I mean, I was told driving to work a counselor called me on the phone on the way to work and said by the way, you are positive. I pulled over to the side of the road and I thought I'd be great but I just started crying because I had fear. So I did everything I was supposed to do. I was not forthcoming as much with my family. Since then some people have been tested and they have been positive and the people have not been tested we don't know.

I agree, I think the support that you guys give is amazing. I would have loved to have had that at that time. I do feel that being tested helped save my life in many ways. I wouldn't have known otherwise what to do today. But I have guilt, I have a lot of guilt about passing it on to the next generation and that's my own stuff. So I try to let that go but otherwise I get tested every six months. I go for an MRI and every six months, I go for a mammogram and I have been completely healthy. So I've been very lucky and I'm very grateful that I'm able, you know to have had this experience and been had the awareness which I feel is more prevalent today than it was in the past.

Bonnie Beckoff: Thank you, Debbi. That was really amazing. We are so grateful that you shared your experience, and I am sure many of our listeners tonight feel comforted by hearing your experience as they may have been through a similar situation as you. If anyone listening would like to connect with a peer supporter, please contact Sharsheret and a member of our support team can assist you.

IV. Question & Answer

Bonnie Beckoff: We will now begin our question and answer period. Again, you can type your questions in the text box located to the right of your screen. We have been receiving questions throughout the webinar. So we are going to delve right in. The first question is, I have a strong family history of breast cancer, but my genetic testing is negative. What does this mean?

Peggy Cottrell: So we know that there are lots of genetic factors that haven't been discovered yet that can be predisposing to cancer. So when we have someone with a strong pattern in their family, we have to figure that there's a possibility that something could have been inherited that is concerning. And so each individual who is in this situation needs to have their family history evaluated to determine exactly what kind of screening has to be done going forward.

Bonnie Beckoff: Here's another question that came in if I last tested ten years ago and have the BRCA2 mutation, should I get tested for one of those new panels?

Peggy Cottrell: So in general what we say is if you carry a mutation In in BRCA1 or BRCA2. The only time we would encourage you to be tested again is if there was something in your family that really didn't couldn't be explained by a BRCA1 or 2 mutations. So for example, if someone has a BRCA2 mutation but a one side of their family, there's a whole lot of colon cancer. So a lot of colon cancer is not going to be explained by the BRCA2 mutation and so it could be possible that there is a second mutation that's causing cancer, but I will tell you it’s pretty rare for people to have more than one mutation. And so generally people who have tested positive don't need to have an updated test. Now people who had testing 10 years ago and the results were negative. That's a different question and it in that case it would be important to consider having an updated test because ten years ago most tests would have only looked at BRCA1 or 2, and again you saw that there are a lot more genes that we can look at now and sometimes something helpful can be identified.

Bonnie Beckoff: Perfect. Okay. Another question just came in: A female child's paternal grandmother had breast cancer and was never tested for BRCA, should she be tested, should her son's be tested. What's the right way to go about this?

Peggy Cottrell: So obviously once people have passed away, we can't go back and test them. Sometimes people ask, Oh, I have a little bit of have hairs from the hairbrush. But we can't really do any kind of decent genetic tests unless the person is alive and we can get a sample of blood or saliva. So this isn't going to be a case where the first or second degree relatives can absolutely get tested based on the family history and in general it's going to vary from family to family. But usually the person who is closest to the person who had cancer, so in this case, it would be the granddaughter, would be a good person to have testing first, and then if something was identified or if there was risk on the father's side of the family in either case, then the person could go on to be tested. And again, I'll say these are generalized answers. If you have specific questions about your own family, then absolutely give us a call and set up a time to talk to me.

Bonnie Beckoff: Here's an interesting one: I'm a man with an immediate family member and uncle with pancreatic cancer, is there anything to do to mitigate my risk?

Peggy Cottrell: So pancreatic cancer can be associated with BRCA2 to a lesser extent with BRCA1. And then also with a bunch of other genes that are on the panels that we test. And so if you have a relative who died of pancreatic cancer, then absolutely you are likely to be eligible for testing. Now, the downside is you know, we talked about how we have really good screening for breast cancer. We don't have good screaming for ovarian cancer, but we can prophylactically take women's ovaries out. But with pancreatic cancer, we don't have either of those options. There isn't really good screening for pancreatic cancer and we can't prophylactically take people's pancreas out. You can't live a really healthy life without a pancreas, but there are studies that are being done all the time to try to find good ways to screen for pancreatic cancer. And so again, that would be a good reason to come in and get a genetic test.

Bonnie Beckoff: Do you guidelines support testing even if my only risk is being of Ashkenazi Jewish descent?

Peggy Cottrell: So this is a very good question and I get this question a lot. If there's no family history of cancer, then insurance is very unlikely to pay for the test. But nonetheless, sometimes we are still concerned that people who don't have a family history may have a small family or may have a family that predominates in men, and there may be reasons why there isn't a strong family history that goes along and so if people are just concerned about Jewish ancestry, they can consider paying for a test out of pocket. It's possible to get a good test for about $250.

There are also studies and there was a study called “The before study” that's available not in every part of the country but in some of the major areas around some of our bigger cities, and that's a way to get free testing. So if you want to get a test done and don't qualify with your insurance, it is something that you can pay for yourself. But again, we want to encourage people, if you're concerned about cancer and you're going to buy a test you want to have a medical grade test not a direct to consumer tests, because that's not going to be a test of really a good enough quality to be able to identify cancer genes.

Bonnie Beckoff: Thank you. This one just came in also, what is a founder gene or founder effects?

Peggy Cottrell: So founder mutation is a mutation that starts and that's why we use the term founder in a particular individual and all mutations before their inherited from parent to child. They all start out at some point being brand-new and then that brand new mutation goes on to be passed to a number of the descendants of that person and gradually make their way through a population. So there are three founder mutations in BRCA1 and BRCA2 in the Ashkenazi Jewish population. These founder mutations occurred, scientists estimate over 2,000 years ago. So they happened really before there was a separation between Ashkenazim and Sephardim. But based on many factors that occurred in Eastern Europe, these mutations were concentrated among Ashkenazi Jews, so that they're more common and not so concentrated among either Mizrahi or Sephardic Jews.

There are founder mutations in many populations, not just in Jewish populations, but for the most part they don't make up a large portion of the possible mutations that can be there. And so generally we do and especially nowadays that doing a bigger test are much less expensive, we generally encourage people to look for all possible mutations in a gene not just the founders in most cases.

Bonnie Beckoff: Can you talk about how someone should decide to get tested especially if they know they have a history of BRCA?

Peggy Cottrell: So if someone has a history of a mutation in their family, then we do the test a little bit differently and that's because we can do a specific test that looks for the specific change that's in that family and very often depending on the layout where the testing is done. It may be possible; if you have that testing done quickly after the original person is tested, the testing may be able to be done for free. So it's really important. If you have a positive result that you share that information with your relatives and give them a copy of the results so that they can take it to their healthcare provider and make sure that the test is done covers the mutation that's been identified in the family.

Bonnie Beckoff: So I think we have time for two more questions. The first one is what are the first steps if I decided to go get testing?

Peggy Cottrell: Okay. So the first step is to find someone who offers the test and so you can start out by asking your doctor. There are some doctors who offer testing in their office. We think that it can be beneficial to use the services of a genetic counselor or another genetic expert so that you get the correct test and the correct interpretation. So if you want to find a genetic counselor, I generally tell people to go to the website of the National Society of Genetic Counselors, and you can find that at NSGC.org. And if you go to that website, there's a hexagon there that says find a counselor you click on that you click on in person and then you're going to do a search function that involves putting in some data points. The first is your ZIP code. The second is to choose the specialty cancer, and when you do a search, you'll come up with genetic counselors who are available nearby to your home, which is identified by your zip code and then you can call those genetic counselors and ask the questions. When can I get an appointment? Do you take my insurance? And decide how to pursue that in general all genetic counselors are sending test to the same small number of labs. So if you go to a big center in a city or if you go to a small community hospital to genetic counselors in both of those places are all sending the test to the same lab. So you really can feel comfortable going someplace that's close to home, because the only difference is really the personality of the person you're talking to the tests are going to be the same.

Bonnie Beckoff: Thank you. So this last question is do you have to have Jewish ancestry to contact Sharsheret? So Peggy you're more than welcome to answer it or I can?

So at Sharsheret our expertise is with Jewish genes and Jewish breast and ovarian cancer. All of our services are there for everyone no matter religion age demographic. We are here to provide all of our resources all of our Says our clinical team our Outreach team. We are here for everyone. So please don't hesitate to call in.

V. Conclusion

Bonnie Beckoff: I think at this time we're going to conclude with our question-and-answer session. Thank you so much Peggy for that really wonderful spectacular educational information that you gave us at the end of our webinar tonight.

You will all be receiving an evaluation in your email in the next couple of days. If you could please take a few minutes to complete the survey. Your feedback is valuable to us and we are committed to staying relevant by enhancing our program to reflect these growing and changing needs of the women and families of our shared community.

A video and transcript from tonight's presentation will be available on the Sharsheret website. You can access it by going to www.sharsheret.org/resources/teleconferences-webinar

I would like to again thank AstraZeneca, Myriad, The Centers for Disease Control and Prevention, The Florence and Lawrence Spungen Family Foundation, The Marcus Foundation, and the Seigmund and Edith Blumenthal Memorial Fund. I also want to thank again Peggy for masterfully helping us navigate genetics and Debbi for sharing her story and bringing their issues to light.

I hope that tonight's webinar was his help was a helpful guide to navigate your genetic history for more information or to speak to Peggy about your personal risk. You can visit us at www.sharsheret.org or call us at 866-474-2774. Thank you so much for joining us and have a great rest of your night.

VI. Speakers' Biographies

Peggy Cottrell, MS, CGC, is a graduate of the Sarah Lawrence College Master of Science in Genetic Counseling program. At Sharsheret, Peggy consults with women and families and answers individual questions about their family histories, BRCA mutations, and personal risks of hereditary breast and ovarian cancer, and contributes to the development and implementation of Sharsheret's hereditary cancer resources and programs.

Debbi Spungen, Debbi is a graduate of the University of Wisconsin-Madison, where she studied Psychology and Social Work. She then worked at Peer Bearing Co for 25 years as VP of Operations. At the same time she was a single mother to her daughter Melissa, who also graduated from Madison. Debbi is a carrier of the BRCA gene mutation and involved in the education of Genetic Testing. She has also been the family caregiver for her parents and understands the need for support in this field. She has studied the Holocaust through the Illinois

Holocaust Museum & Education Center. Today, Debbi splits her time between Illinois and California as she likes to volunteer for organizations which the Foundation funds. Her personal philanthropic interests are mental wellness and health related issues.

VII. About Sharsheret

Sharsheret, Hebrew for “chain”, is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret’s Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

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

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus

- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

VIII. Disclaimer

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

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