Beyond BRCA:

Myths and Facts about Your Cancer Risk

National Webinar Transcript

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Presented by:

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Melissa Rosen:

Okay, it's time to get started and it's so nice to see where everybody's logging in from welcome. I want to thank everybody for joining us at Sharsheret tonight for Beyond BRCA Myths and Facts About Cancer Risk. Tonight, we're going to take a deeper dive into hereditary cancer, including a number of mutations that impact risk for breast cancer, as well as several other types of cancer. We'll also explore who's impacted by these mutations and in that process; we're going to hear from to Sharsheret callers. My name is Melissa Rosen; I am the Director of Training and Education at Sharsheret and again, thank you for joining us.

Before we begin, I have a couple of quick housekeeping items I need to share. I want you to know that this webinar is being recorded and will be posted along with a transcript on Sharsheret's website. Please note that participant's faces and names are not included in this recording but if you'd like to remain private even tonight, you can do so by turning off your video and changing your screen name. Alternatively, you can choose to call into the webinar and instructions for that are in the chat box. You may have noticed all participants were muted upon entry, please stay muted throughout the presentation. We recommend you keep your screen on speaker view so that you will be able to see the presentation clearly. You can find this option in the upper right hand corner of your screen.

I have to say we received so many really insightful, impressive questions before tonight's webinar and I expect there will be additional ones now. Please use the chat box, which you can access at the bottom of your screen to type in any questions and we will do our best to answer all of them. Any questions we don't get to tonight will be addressed by email over the next week. I do need to remind you that Sharsheret has been providing telehealth services for the breast and ovarian cancer communities for almost 20 years. And the pandemic has not changed that; we continue to be there for each and every one of you.

One of our many programs to help women and their families navigate the cancer experience that may be of particular interest to those on tonight's webinar is our Genetics for Life program. As a part of that program, you can speak one-on-one with our certified genetic counselor that you'll be hearing from tonight about family history, concerns about cancer risk, the implications of genetic counseling and testing for you and your family. And you can actually even have a family conference call you can gather your family on a call to let us help communicate with them about hereditary risk and proactive steps that each family member can take. And as always, all of our services are 100% confidential and 100% free.

As we move into the webinar itself, I want to remind you that Sharsheret is a national non for profit organization and we provide cancer Support and education but we do not provide medical advice or perform any medical procedures. The information provided by Sharsheret is not a substitute for medical advice or treatment for a specific medical condition. You should not use this information to diagnose or treat a health problem as always seek the advice of your physician or qualified health care provider with any questions you might have regarding a medical condition.

Okay, so let's get to it. We are so lucky to have Peggy Cottrell as not only a member of our Sharsheret team year round, but as tonight's main presenter. Peggy is a certified genetic counselor and a graduate of the Sarah Lawrence College Master of Science in genetic counseling program. At Sharsheret as our Genetics Program Coordinator, Peggy consults with women and families and answers individual questions about family history, BRCA and other mutations, personal risk and more. And she has a very valuable and all too rare skill of making a complicated topic clearly understandable. Before I turn the program over to Peggy we've created an interactive opportunity as part of tonight's webinar. Throughout her presentation, you will see polls pop up on the screen to challenge your knowledge and

expose myths related to hereditary cancer genetics. We encourage you to participate and the answers to the polls will also be posted live. Thank you, Peggy. Let's get started.

Peggy Cottrell:

Okay, great welcome everybody to our presentation tonight, and I'm going to share my screen here. Okay. Please go ahead and answer that poll. Okay, so what percentage of breast cancer is inherited 2%, Five to 10% 30 to 40%, or more than 50%? Okay, and it looks like you know what I'm going to have to stop share and reshare. I'm very sorry. I'm having a problem. I'm very sorry about this. Okay, now I'm on the right slide. So it looks like we have a smart group here, because for the most part, people selected the correct answer, which was five to 10%. So most cancer happens for reasons that we can't explain. A lot of it has to do with things in the environment, our lifestyle factors, and a big chunk of it is just chance.

Different cancers are more or less likely to be inherited depending on the type. So breast cancer, we think about five to 10% of the time is related to a strong inherited predisposition. Ovarian cancer it's probably more than those other cancers less. Anyone can get cancer. And cancer arises in our bodies, as there are genetic changes that happen not in our inherited cells, but in cells anywhere in our body. And as those changes accumulate in our body cells over time, gradually change our normal cells into cancer cells. Now, if someone has an inherited mutation, it means that they start one step ahead on this pathway. So instead of starting at normal cell, someone with an inherited mutation starts at the one mutation point. And you can see on this pathway that if someone starts with an inherited mutation, it's more likely that they'll develop cancer and also because the pathway has become shorter, it's more likely that it'll happen to them at a younger age, but someone could have that first mutation, and never develop the additional mistakes that it takes to develop cancer. And so that's a little bit of explanation here.

So let's go to the next poll. This is our quiz two and the question here is, what population should worry about BRCA1 and 2 carriers? Ashkenazi Jews, Ashkenazi Jews and those with European ancestry or anyone of any ethnicity. Okay, and we have a mixture here of opinions on this, and I'm going to tell you that it's the last one that's correct. Really, anyone of any ethnicity. Anyone, anywhere around the world can carry mutation in BRCA1 and 2 and in any cancer predisposition. I think there's a misconception out there because Ashkenazi Jews have a higher risk, one in 40, compared to more like one in 400 in the general population, that Ashkenazi Jews are the only ones who have to worry about this.

And there's a second misconception there, that it is only white populations that have to worry about and not people of other ethnicities. But it turns out if we look at how often people around the world carry mutations in BRCA1 and 2, we see the same thing in populations throughout Africa, throughout Asia, South America, North America, there are very few populations where we see an increased incidence, but one of those is Ashkenazi Jews and so we have to be more careful in our community, but anybody can carry mutation in BRCA1 and 2. And then finally my first sentence, I just want to remind everybody that men are just as likely as women to carry these mutations. And so even though a woman who has a BRCA1 or 2 mutation has a higher chance to develop cancer than a man does, men still do develop cancer related to BRCA1 and 2, and they can pass it to their unaffected their children, their offspring.

So let's move to the next poll. What type of cancer is likely to be hereditary? So number one, lung, skin and cervical cancer. Number two, breast and ovarian cancer. Number three, breast, ovarian, colon, uterine, pancreatic, prostate, melanoma and stomach cancer or number four, all cancers are hereditary. So, choose your answers, and then we'll see what is correct. So we have a mix of so, first of all, I'll tell you by not choosing number one, you're correct. Those are cancers that are almost always happening by

chance but the correct answer is number three. So when we're looking at a family tree for cancers that could be inherited, we're looking for cancers like breast, ovarian, uterine, colon, et cetera. When we see other kinds of cancers, those don't add into the formula. But we're looking for all of these other cancers and lots of other genes because we're able to do a test that's much more comprehensive nowadays.

So if you look at our little diagram here, we see breast cancer in the first one, and then the surrounding it, we see lots of different genes that can predispose to breast cancer. And I'm not going to read all of the names, because that's somewhat less interesting. But many different genetic mutations can lead to the development of breast cancer. And in the same way, in the second small picture, we see a genetic mutation, TP53. And mutations in TP53 cause a lot of different kinds of cancer and you can see many of those cancers surrounding the TP53 diagram breast, ovarian, gastric, colon, pancreatic, melanoma, prostate and endometrial. And so we see that each gene that we look at has a different pattern of the cancers that result. And so it's not that we're looking at lots of other mini BRCA1 and 2 genes. But in fact, all of the other genes that we look at have their own particular unique pattern of cancers that develop. But because of the overlap between one syndrome and another, we tend to do current testing as a panel.

And so if you go in nowadays, to get a test for BRCA1 and 2, you can still get a test for only BRCA1 and 2 but typically, you're going to be offered a panel that can include anywhere from 25, to as many as 85 different genes on it. And some of those are going to be very obscure and cause very rare kinds of cancer; some of those genes are going to increase the risk for cancer in a very subtle way. So it's really important when you get a big test like this done not to understand all the genes ahead of time, but to make sure that if you do test positive, you get a very careful explanation of what the implications are for the gene that was identified.

Okay, let's go to our next quiz. So hereditary cancer affects only children, mostly women, rarely men, only women, or both men and women depending on the type? Want to collect your answers and we'll see what we get. Okay, amazing. You guys are super smart because that is the correct answer. 98% have chosen our correct answer. So we want to really emphasize in tonight's webinar that this is something for men to be aware of as well as women. And so certainly men with mutations in BRCA1 and BRCA2 are at an increased risk for cancer not as much as women but they may develop prostate cancer, pancreatic cancer, and melanoma or male breast cancer. But importantly, many of the other genes that we look at, can cause more risk to men. So for example, men could be at an increased risk for colon cancer, and for other cancers if they're carrying these gene mutations.

Let's go to our next poll. So if someone's a carrier for hereditary cancer, let's... I forgot to change the slide here. Okay, someone's a carrier for hereditary cancer, what's the chance they will get cancer? Okay, and so most of you have chosen the correct answer, which is four, depends on the gene. But there's a reason why this is tricky and that's probably because really all of them are correct, because it depends on the gene. So sometimes, we do a genetic test we find someone is a carrier but their risk to develop cancer is still pretty low, maybe only 10%. Sometimes it's more like 50%, 87 is a number that gets quoted a lot of times for the risk of breast cancer with BRCA1, which is why pick that somewhat unusual number, but it's really important to understand that it depends on the particular gene, what is going to be the risk. And so I'm going to mention a couple other genes that we want to look at here.

So there's a mutation that's very common in people with Ashkenazi ancestry, it's in a gene called APC. And APC is a gene that predisposes to colon cancer and there's mutation that's common in about maybe as many as 10% of Ashkenazi Jews. And very often, when we get testing done, this is one that pops up, it's called I1307K and it's a very specific change that's common in APC, in the Ashkenazi community. And someone who carries this mutation instead of having a five or 6% chance to develop colon cancer has about twice that. So maybe they have about a 10 to 12% chance to develop colon cancer.

And this could be enough to lead to a change in screening it can be important to find out about, but overwhelmingly, when we might be looking for something else, and we're testing someone with Ashkenazi ancestry, this finding can pop up. But obviously with BRCA1 and BRCA2, the risk to develop breast cancer can be very high, somewhere between 50 to as much as 85%. And so, depending on what the risk is, for each of the different types of cancer, someone may choose to be taken care of in a different way.

Okay, so now we're up to our next quiz. If someone carries a mutation in BRCA1, what should they do? They could have a bilateral mastectomy, add an annual MRI to their breast cancer regimen, remove their ovaries and tubes between the ages of 35 and 40, all of the above are recommended or only one and three are recommended. This is a trick question. This is like one of the hated A, B, C, A and C, B and C, all of the above, none of the above. Okay, very good. So you guys have done well on this question again because this one is really all the above are recommended and it depends. And I want to talk about this a little bit more.

One of the questions that I very often get from people who are wondering if they need to have this test done, they'll say to me, "Peggy, listen, I'm already super careful, I get my mammogram every year my sonogram. My doctor examines my breasts. Why would I really need to know if I have a BRCA1 or 2 mutation?" And the reason why is besides and these people will say, "Listen, I'm not having prophylactic surgery. I don't believe in cutting out body parts, but tell me why I need to have this test done?" And the reason why is we make a big difference by adding screening. And so individuals, women with a BRCA1 or BRCA2 mutation will qualify for high risk breast cancer screening which includes adding an annual MRI to their screening.

And by adding that annual MRI, we increase significantly the detection of breast cancer enough that we really feel comfortable giving women a choice. We don't say to women, if you have a BRCA1 or 2 mutation, you have to have a prophylactic bilateral mastectomy that might be a good choice for some people. But for other women, the better choices to careful screening. But it's really important that the careful screening include the MRI. And that's because the studies that are done seem to show that the specificity and sensitivity of the MRI really improves our ability to find the breast cancer at the very earliest stage. Now, I think probably, if you carefully examine this statistics you could see that there is an edge of a benefit to the double mastectomy, but not so much that we'd require people to go down that pathway. So again, to my person at the beginning, who says why do I really... I'm already being careful about my screening. The point here is that there is an additional screening test that can really improve detection and it's available to people who really know their risk. A breast MRI does not make sense for people at average risk; it really makes sense for people who have that additional higher risk.

So we'll move on to quiz number seven, if someone is already diagnosed with cancer, number one, it's too late for a genetic test to help. Number two it can help guide treatment. Number three, it can help interpret testing of a family member or number four, both two and three. Okay, another excellent poll result by the group. Thank you. And let me explain a little bit of why this is the case. Okay, so very often women will say to me, you know, I already had cancer. So how does it make any sense for me to have this test? How's it going to do me any good? Its too late cancer already happened. And so there are three good reasons why it's important if you've had cancer to have the genetic test. And the first one is that positive results can help inform the negative results of other people in the family. And what does this mean?

So let's imagine a scenario let's say that I have cancer, I got breast cancer when I was very young and so now my daughter is worried, is it going to happen to her? So she goes to her doctor, her doctor gives her the genetic test, and the result is negative. So she might say, excellent. I'm not at increased risk. But it turns out that there are things that predispose to cancer that are inherited that we don't know how to

look for yet. And so my daughter's seemingly negative result, if I don't get tested, we're not sure what it means. And so when someone in the family who doesn't have cancer tests negative for mutation we call those uninformative results, when there is no one in the family who's tested positive. And that's because we don't know why I got cancer in the first place.

So if we change the story, and now we say that I got the genetic test, and I test positive, so now we know what's causing my cancer and if my daughter gets the test and her result is negative, then that's what we call a true negative result. And someone who has a true negative, it doesn't mean that they're never going to get cancer, because we said already at the beginning, anybody can get cancer. And it even happens to people who are in families with people with an inherited mutation, and their result is negative. And I can tell you, I see that many times when testing people in a family, someone in a family with an inherited mutation develops cancer, they say, "Ah, I must have the mutation." And it turns out that they don't. So that's the first reason why it's important for the affected person to get tested.

Second reason is that for most inherited cancer genes, there is more than one type of cancer that's increased. And so let's say I develop breast cancer when I'm 40 and I don't get the genetic testing done, but I do very well. I get treated my breast cancer is cured. But then when I'm 50 I come down with ovarian cancer. So that's what we're trying to prevent when we do the genetic test. You got cancer once; we don't want you to get cancer twice. So again, that's a second good reason. And the third good reason is that now we have targeted medications and so there are medicines called PARP inhibitors, which are sometimes available for those with inherited mutations to take to help treat their actual cancer. And these medications were first studied with ovarian cancer, and they have been proven to work really well with ovarian cancer. They're also being studied and work well in breast cancer and prostate cancer, and in pancreatic cancer.

And so again, really important for someone, especially with an advanced cancer to get genetic testing, and most insurance companies now actually have a diagnosis of an advanced or metastatic cancer is a reason to allow for genetic testing even in the absence of family history, because of the possibility of looking for a targeted medication. Okay, let's go to the next quiz. Who will inherit a BRCA1 or 2 mutations? Only the daughters, all of the sons and daughters, half of the children will get it, each child has a 50% risk to inherit it. So make your choices. Okay, so you see those polls, and again, we have a smart audience, the correct answer is number four. And I'm showing you here an example of a pedigree and this is how genetic counselors and other genetic experts draw out family trees.

And so when we draw a family tree, the squares are men because men are square. The women are circles, we put a line through people who are deceased and usually we either color in or put little wedges in that show people who have been affected. So you can see in this particular family tree, the first person at the top, that's the grandparents and the first person that had this particular mistake, was the grandfather. And there was a 50% chance that he could pass this mutation on. And in this particular case, there are special cases where there are genetic diseases that are linked to X or Y-chromosomes and that's more complicated. But here we're talking about genetic disorders that are traveling on the numbered chromosomes, which are the same in men and women. And so in that case, it's 50/50 chance of being passed on and you can see he passed it to a son and to a daughter. And then the daughter also passed it to a son and a daughter.

Sometimes people, by chance, have an inherited mutation and don't pass it to any of their children and that is awesome. Sometimes people have an inherited mutation, and they can pass it to all their children. I once worked with a family where six siblings had previously tested positive and she the seventh also tested positive. So that's unlikely odds, but it's each individual has the same 50/50 chance. So sometimes people think, well, you know, my brother and sister already tested positive, so chances

are I'm not going to have it. But that's actually not the way it works and we know this from flipping coins that each time you flip the coin, it's 50/50 and it doesn't matter what the previous flip was.

So let's move to the next quiz. If you test positively for cancer genetic mutation, you will lose your medical insurance. Two, your children will lose their medical insurance. Three, you may be denied or be charged a higher rate for life disability or long-term care insurance, or all the above. Think about it. Okay, so again, a smart audience has mostly chosen the correct answer. So I'll explain to you just briefly a little bit about the laws that are related to genetic discrimination. There is a law called GINA, which stands for Genetic Information Nondiscrimination Act. And this law prevents medical insurance from discriminating based on some kind of genetic finding. Now there's additional protection for medical insurance in the Affordable Care Act but what I like to remind people of as we wonder what might happen to the Affordable Care Act, that there is pre-existing protection in this law for genetic mutations and medical insurance. There are a couple of small exceptions to this law; one of them is the military. So if you have questions or concerns you should need to speak to an expert.

Life, disability and long-term care insurance may be affected and it depends on the state. And one of the interesting things that just came out in the last month or so is one of the first states, Florida has passed the law to protect people with genetic disorders from discrimination in life, disability and long term care, which is a really amazing decision by their legislature, so go Florida. But states vary and I have seen in my own experience that New York can be somewhat difficult.

In my experience, I've had more people with problems with these kind of insurances in New York when I work there than in my practice in New Jersey. And if you have concerns, I've put two web pages on this slide, you can take a look and check out you can always speak with an insurance broker with these questions. And what I generally tell people is, it's more important to have a test that could save your life than to die with good life insurance. And so you really want to make sure put as much as you can put your life insurance, your disability insurance, all of those things in good order before you have the genetic test. But don't use this concern to stop yourself from having a test that you need to have done.

Okay, test 10 your genetic test is negative, what does it mean? You're low risk to develop cancer. You're at high risk to develop cancer. Your risk depends on your family history, or your risk depends on your family history and results of other family members. Okay, very good, good work. So the correct answer is the last one, it depends. And this is related to the story that I explained before when I was talking about my informative or uninformative negative results from my imagined scenario where myself and my daughter we're having testing. When whenever I have someone tell me their result and this happens a lot of times when they have Sharsheret calls they say, you know, I got a negative result, what does it mean? I got a positive result, what does it mean? So it's really difficult for me to explain to someone what the implications of their results are, unless I really am able to look at their family tree and see what's going on.

And that's because if someone has a negative result, but they have lots of people in their family who've had cancer, and none of those people have had genetic testing that's been positive, then we have to surmise that there could be something inherited that we don't know how to identify yet. And therefore that person is still at high risk, and needs to have that very careful screening. And insurance generally allows for that there are calculations that are done by your doctor based on your family history and other parameters that can qualify you to get a breast MRI even if you don't have an identified inherited mutation. It turns out that there are things called SNPs, which stands for single-nucleotide polymorphism. And what that means basically is all of us have DNA that's slightly different from other people in ways that are most of the time not important.

So if we were looking at a particular gene here, we've identified three different people. And here are some people at a particular location in the gene have an A and the alphabet of DNA is G, C, A and T. So

here's some people have an A, some people have a G, and some people have a T. And most of the time these differences don't cause any major change, it might affect what we look like or how tall we are things like that. But sometimes they can have an impact on disease. So let's imagine that the people who have the T, as opposed to the G or the A have about a one half of a percent higher chance to get breast cancer. So that's not very much of a difference but it turns out that there are thousands and thousands of these SNPs that are occurring in our DNA.

And so even if by themselves, they don't make that much difference, if you had enough of them that added up into risk in one particular disease that could actually cause a problem. So SNPs is where we really want to try to go in learning more about all of those families that look inherited and we don't know why that is. And so there are labs that are working on SNP risk score tests but they are really at a beginning stage and most insurance companies aren't willing to accept a score from these SNPs as something to qualify, let's say for a breast MRI or to qualify for a mastectomy.

Peggy Cottrell:

The other problem with these SNP test is because most of the research that's been done in the United States, on these SNPs have been done in white populations. And so people of color can often not get a SNP test, the ones that are available only work for people who are white. So this is another problem and shows again an area where we have a lot more work to do. So that's the end of my presentation. I'm going to stop my share and pass to Melissa.

Melissa Rosen:

Thank you so much, Peggy. I always learn something new when we speak and tonight was no different. I appreciate that. A reminder that there were some wonderful questions that got put into the chat box we're going to do questions at the end. We're not ignoring them. Tonight as I mentioned, we also have an opportunity to hear from two Sharsheret callers. We gain so much insight as we take medical information and hear it through a personal experience and that's why we have callers often share their stories. Our first caller Bill is a husband of 43 years to his best friend, is a proud father of a 35-year-old communication Director and Senior advisor, a caregiver to two wonderful dogs. He's also a former journalist, and a more than eight-year survivor of male breast cancer who also happens to have a BRCA2 mutation. Bill?

Bill:

Thank you very much, Melissa. Everyone can hear me good?

Melissa Rosen:

Yes.

Bill:

Okay. Well, thank you for this opportunity I as Melissa said, I am an eight and a half year survivor of a male breast cancer. And before I diagnosed myself, in fact, I was not aware of the fact that men could get breast cancer. Eight and a half years ago, there was very little literature about it and I woke up one morning with a blood spot on the T-shirt that I slept in. And I didn't think much of it, I had a dog that had had some eye surgery, and I thought maybe it was just a little weeping from that. And the next morning, I knew that she hadn't been near me and I had a clean shirt on, and the spot was there again. Pardon me and that was at about six in the morning and by about seven o'clock in the morning I was pretty certain that I had ductal cancer. I had to wait until nine o'clock to get to call my doctor to get an appointment.

Got a typical male response in that the receptionist and office manager went completely silent when I mentioned that the reason I needed to see the doctor that day and not in 10 days was that I thought I had breast cancer.

At that time, and even to this date, men are not really thought of and included in the discussion. And within five weeks, I'd had a mammogram in a pink paper robe with a technician who had never done a mammogram on a man. An ultrasound also the technician who'd never done a breast examination on a man and a needle biopsy and it came back positive. And so within five weeks of my figuring out that I had breast cancer, I had my first mastectomy. Because I was so proactive because I reacted so quickly I was extraordinarily lucky, thank God. And it was after the pathology reports and all I was classified as stage zero. My oncologist put me on tamoxifen because it was an ER positive cancer. And then I started doing additional research and started learning about the genetics of breast cancer and learned about the BRCA gene mutations.

It took three requests of my insurance company to approve my request to have the gene test done. There was only one company at the time that did it company called Myriad. And they didn't allow anyone else to use their technology to examine those specific genes. Came back positive and with more research recognized the fact that this was something that was passed on to me by my parents, one of them or both. My father was not living at the time, so we couldn't get him tested. But my mother got tested and my sister got tested and my son got tested. And between them all, my mother was the only one who was negative. My sister and my son both were BRCA2 positive.

I went ahead and scheduled a second mastectomy prophylactically I didn't want to have to live with the fear that I would get breast cancer again or one of the other cancers which I couldn't really prepare for other than being diligent. My son chose to have prophylactic double mastectomy with reconstruction. My sister chose to just be very diligent and up the frequency with which she was having exams. Everybody is healthy right now and in looking back at my family tree, we realized that on my father's side of the family, there were a large number of incidences of breast cancer, ovarian cancer, and a number of the others. Most all, in fact, all that I was able to determine in women, we're not able to find out if any men in the family also had breast cancer.

So I've been on a soapbox ever since and I have addressed many different organizations. I frequently talk to groups at Los Robles Hospital in Thousand Oaks, I talk to a number of other groups I'm a member of four or five different support groups and I do peer counseling. The testing genetically for me was very important because it did several things. It enabled me to eliminate the issue to my family, to make sure that my son took care of this and was informed to make sure that my sister also was as well. And that was really, for me, extraordinarily important. I wanted to make sure that everybody was armed with as much information as possible and so my son now knows that though he is... Has a higher risk for a number of other cancers because of the BRCA2 mutation. He knows that he's not going to have to worry about breast cancer as one of them. So my having gone in is a blessing in a way.

Melissa Rosen:

Thank you so much, Bill for sharing your story. It was a perspective we don't hear as much about as we should, like you said, and like somebody commented, and so we're grateful for that. Thank you very much.

Bill:

My pleasure.

Melissa Rosen:

Our next caller is Lindsey. She is a breast cancer survivor who originally tested negative for BRCA mutations only to find out that in fact, after her diagnosis she learned she had a mutation called PALB2. She was a huge advocate for knowing your genetic status, as well as someone who is involved with many Facebook groups and support groups. She shares her story in the hopes that it can save others, so Lindsey thank you for [crosstalk 00:44:40] with us.

Lindsey:

Thank you so much for having me. I appreciate the opportunity to speak to you all tonight. I always knew breast cancer was a part of my family. My paternal aunt had breast cancer at 38 and 39. Her paternal aunt had passed away from the disease in her 40s, my great grandmother, my great grandmother's brother, and my great grandmother's sister all had breast cancer. So I started proactively getting screened in my late 20s. I would have an MRI and a mammogram every year spaced six months apart. But I struggled with getting the mammogram paid for unfortunately, because they always claimed that, well, your mother, your child, or your sister didn't have breast cancer. Now, as you know, my family history is on my father's side I have a brother and I have two sons. So that was really frustrating for me. But nonetheless, we still continued on and in 2013, I went to see a genetic counselor as you mentioned, Melissa and I had the BRCA testing and which turned out to be negative.

However, the genetic counselor at the time told me, "You know what, there's something there that we don't know about and I would just strongly suggest to you that you continue on your screening regimen and continue to be examined." And thank God she said that because those words literally saved my life because exactly a year to the day of my BRCA1 or 2 tests, I was on the operating table getting a double mastectomy, because I had been diagnosed with breast cancer at 36 years old. My kids were five and seven at the time. It was very challenging. I ended up having chemotherapy because of oncotype score, my family history and my age.

But the day before I started chemotherapy, I saw an article in The New York Times and it talked about the PALB2 genetic mutation. So I brought the article and said to my doctor, "Hey, can I be tested for this?" And she said, "Sure. We have to do a full panel." And the PALB2 mutation was one that I ended up having. So I went through treatment went on tamoxifen, had reconstructive surgery and I never felt quite right after my chemotherapy I still was very fatigued. I was told it was going to take a while for the chemo to get out of body, but I just deep down, I didn't feel like there was anything. I felt like there was something wrong.

And in 2016, I was having some pain in my arm and I thought, oh, well, maybe I'm having a bout with lymphedema. I was node-negative when I had my double mastectomy and I was classified as stage one. But I felt a lump under my armpit and I was kind of poking around and found it and brought it to my doctor. And they were like, "Oh, it's nothing, nothing." I had three different doctors actually and when I went to my normal oncology appointment they said, "Let's check that out."

And it turns out; I had localized recurrence of my breast cancer. I went and had an axillary dissection, where I had 14 lymph nodes removed and 10 of which were positive. So I was back in chemotherapy, had radiation this time, I chose to have my ovaries and tubes removed. But I was told because of my mutation that they were treating my cancer similar to a BRCA2 mutation since PALB2, so yes the Partner and Localizer of BRCA2. So you know, thankfully I've been healthy ever since I get CT scans now every year but there have been some barriers in my family because of that mutation I have a first cousin who decided she wanted to get tested. And her insurance company said, "No, you may not, you need to prove that someone in the family has this mutation." So she asked to call me and asked me for my, you know, "Hey, would you mind sharing your results with me?" And of course, I did.

But it's amazing that just a few years ago, this is still an issue. And other than that cousin, we are the only two in the family that have been tested. And my children have asked, "So when do I get tested?" I have a 14 year old and 11 year old. And they've asked the question and I've answered it as honestly as I can. But it's a complicated thing and I'm sure some day they will be tested and I'm encouraging other family members to get tested. And that's my story and thank you guy so much for allowing me to share.

Melissa Rosen:

Thank you very much. You know, it's not always easy to share personal stories, but it's so instructive to those who hear it, it really it reminds us that we need to be proactive about our own health. And it really does, it saves lives through education. So thank you for that. So we have a few minutes left, I want to get to some questions but I also want to assure everybody that all questions will be answered even if not by tonight on but by blog post which we will send to you and or write email. So if your question wasn't answered, please don't worry. Let's start with a first question. So one is how do I know when I should pursue an updated test and at what age should I consider screening if I haven't screened yet?

Peggy Cottrell:

So the age to consider having a genetic tests done, we don't test children generally, so you're old enough to have a test done when you're 18. The age when we might do something differently is probably more like 25 so that can be a good age to have the testing done. But in terms of an upgraded test, so someone who only had testing for BRCA1 and 2 is definitely a person who should consider an updated test. A panel test can be done even without insurance for $250. So people sometimes worry oh, this is very expensive. I can't afford thousands of dollars. This test no longer costs thousands of dollars. There's a lot of competition out there so prices have come down significantly.

And if you're not sure if you had a panel or not, or how long ago it was, you can get a copy of your results from your doctor and speak to a genetic counselor. It's one of the questions I feel very often at Sharsheret callers call in and say do you think I need to have another test done? And I can take a look at your test and your family history and let you know if that's a good idea.

Melissa Rosen:

Thank you that was very helpful. Somebody asked what happens with if both parents carry either the same mutation or two different mutations that raise risk?

Peggy Cottrell:

So very often if people carry two different mutations, they don't add together. And so usually, you have the risks that go with each one. But if those risks are the same, it doesn't double. And having different mutations, again, doesn't seem to cause any problem. Sometimes, if the same mutation is present in both parents, and they pass the same mutation to the child it can result in a genetic disorder that's much more significant. And that in the case of many of the breast and ovarian cancer genes like BRCA1 and 2, that's Fanconi anemia.

Sometimes it happens also, with Lynch syndrome, people can inherit... Lynch syndrome is a syndrome that predisposes to colon and uterine cancer and if someone has two mutations in the same Lynch gene that can also cause a more severe presentation in a child. So it's always worth thinking about if you have a strong family history of cancer to get a genetic test before you have children.

Melissa Rosen:

Thank you for that. Someone asked when and how to tell... You know, the interesting question, this person asked about sharing this information with daughters about their possibility of carrying a mutation. So now they understand it won't just be after tonight's webinar, it's daughters and sons that need to worry about it. But how and when should we start making this connection for our children?

Peggy Cottrell:

So it's a very complicated question and I will share that we have a booklet Sharsheret that we're happy to send to you called How Do I Tell My Children About My Cancer Gene? And every family has to make this decision in a different way. So someone might tell their children about the inherited mutation well ahead of when their children are old enough to actually be tested. It really depends on the family, and how you want to share that. But again, we don't test children because children can be affected with cancer and we want to preserve their right to decide if they want to be tested or not once they are adults. And so just like when we tell our kids about sex, we do it in a very slow and developmentally appropriate way.

So the first time you get a question, you're not going to share all of the information, but you might start with your kids by telling them, you know, mommy had cancer and so I have to take very good care of myself and I go to the doctor to get regular checkups and I take you to the doctor so you get checkups. And we do that so that we take care of ourselves. And then the next step is sometimes cancer could run into family and so you know, my sister is also careful to get her checkups, and then finally progressing to there's something inherited in our family and I carry it and I might've passed it to you.

So in a stepwise fashion, you're gradually educating your children about what this means. It's not an easy thing to do. It's hard to do. But we're here at Sharsheret to help you with materials so you can get some booklets that can make it easier to talk about these things with your kids. And you can have me do family conference calls if you feel like you want to have a conversation across the miles with a genetic counselor involved as well. That's also something that we can facilitate.

Melissa Rosen:

So we're going to ask two more questions and then again, just like was in the chat box, all questions will be answered. So one of the things we've started talking more about at Sharsheret and somebody asked in the chat box this evening, is you mentioned that BRCA and some of these other mutations don't just impact risk for breast or ovarian cancer. So are there medical screening protocols for the other cancers that they raise risk for that we may want to partake in if we carry a mutation?

Peggy Cottrell:

Okay, so that's a pretty broad and complicated question. But let's pick a couple of cancers so some of these genes, someone could be an increased risk for colon cancer and with Lynch syndrome people need to have a colonoscopy actually done every year. And that's because with Lynch syndrome, someone is not any more likely than anyone else to develop a colon polyp. But with Lynch syndrome, a colon polyp can change from a polyp to cancer very, very quickly. And so in each case it depends. Now colon cancer, we have very good screening for a colonoscopy, that is really the gold standard, because you can not only find a cancer early, but you can prevent cancer by removing polyps.

There are other cancers, I'll mention ovarian cancer similarly to pancreatic cancer, those are two cancers that are very, very hard to screen for. Now, with ovarian cancer, even though it's hard to screen for women can live very fine lives with their ovaries removed, and so we have that option. But with pancreatic cancer, you really can't live a good life without a pancreas. It's a much more critical organ. And so we're at the beginning with pancreatic cancer of being able to understand a little bit about

screening but I always recommend if people want to pursue screening for pancreatic cancer that they do that at a research center where they're involved in advancing or understanding of screening and pancreatic cancer at the same time, that it may be helping you as well. So any questions about any particulars or another cancer that I didn't mention here in this very quick answer, please don't hesitate to be in touch.

Melissa Rosen:

One very simple question because somebody asked it early, and I want to get it in. So if someone is a man who carries a BRCA mutation, will they also be going for regular mammograms prior to or MRI before there is even a potential diagnosis?

Peggy Cottrell:

No, so there is not really consensus about whether mammograms are of any value in men. And there are some doctors who recommend an annual mammogram for men with a BRCA mutation but most say that a breast exam every year by the physician and then the person who's a carrier themselves has got to get to know their own body and see if something is different in their breasts. And very often, men don't notice changes in their breasts because they're not as attuned to it. Because of breast cancer, first of all, so many men don't even realize that men get breast cancer and men are just, you know, will or are more likely to just ignore something that changes in their body not being alerted the way many women would be. So it's important that you discuss these things with your doctor and get the best recommendation for your situation. I [crosstalk 01:00:36] know regular breast screening generally for men other than a breast exam.

Melissa Rosen:

Okay, thank you. Thank you, Peggy. Thank you, Lindsey. Thank you, Bill and I also want to thank today's sponsors AstraZeneca, the Basser Center for BRCA, the Siegmund and Edith Blumenthal Memorial Fund. This program was also presented under the Cooperative Agreement DP19-1906 from the Centers for Disease Control and Prevention and the Max & Anna Baran, Ben & Sarah Baran and Milton Baran Endowment Fund from the Jewish Community Foundation of LA. We will be posting a brief evaluation survey link in the chat box right now. I want to encourage you to click on it, spend less than two minutes answering those questions it's right there now, because your answers really do inform our future programming.

Again, there were so many questions we didn't get to, I assure you between blogs and emails, these will all be answered and of course if you have deeper questions or uniquely personal questions, you can always reach out to Sharsheret and make a telephone appointment with Peggy to have a deeper conversation. Remember that our social workers and Peggy is our Genetic Counselor is available to each and every one of you. You are our priority; your health, your well-being and we are going to be here for you. So thank you for joining us. Have a wonderful night and don't leave before you've clicked on the evaluation survey, again good night.

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

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