Unraveling Cancer: The Power of Genetics Research

National Webinar Transcript

Date

Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

About Sharsheret

Sharsheret, Hebrew for “chain”, is an international non-profit organization, that 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 regional offices in the Midwest, Northeast, Southeast, West, and Israel, Sharsheret serves 275,000 women, families, health care professionals, community leaders, and students. 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, approximately 25% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, 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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Moderator:

Thank you so much for being here. I want to thank you again for joining us for this important topic, this conversation about the impact of research on cancer and on genetics. And for the purposes of this webinar, we're going to use the broadest possible definition of research that may actually include some unexpected types of research. Our goal this evening is for us to better our understanding of how research impacts us in the here and now and how we can participate in that research.

Moderator:

Before we begin, I have a couple of housekeeping items to share. First, I'd like to thank AstraZeneca and Pfizer and the Basser Center for BRCA for their generous support of today's program. I'm also excited to share that the webinar is being presented in partnership with FORCE and that Diane Rose FORCE's VP of Research will be joining us to answer some questions toward the end of the webinar.

Moderator:

This webinar is being recorded and will be posted on Sharsheret's website alongside a transcript for you to use as a resource. Participants' names and faces will not be in the recording. You also have the option to be anonymous during today's live webinar. The instructions on how to do that are in the chat box right now. Additionally, we now have closed captions available. The instructions to activate them are also in the chat box.

Moderator:

We've received so many really, really deep questions during the registration process that I'm excited for us to answer, but as questions arise during the presentation, and I'm sure they will, please use the chat box and we will be monitoring it and address them during the Q&A at the end of the webinar. As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for almost 25 years, because cancer is so much more than simply a physical experience. If you are interested in finding out more about Sharsheret's free, confidential and personalized services, please email us or visit our website at sharsheret.org, and that's in the chat box too.

Moderator:

As we move into the presentation, I want to remind you that Sharsheret is a national not-for-profit cancer support and education organization that does not provide medical advice. The information provided by Sharsheret and tonight's speakers is not a substitute for medical advice. You should not use this information to diagnose or treat a health problem. Always seek the advice of your physician or a qualified healthcare provider with any questions you may have about your specific condition. Before we dive into the research, we are fortunate to have someone with us to share a personal story. I'm going to bring her up onto the screen.

Moderator:

Betty is our Sharsheret caller who has agreed to share her story tonight so that we can all benefit from her experience. Thank you so much for being here tonight, Betty.

Betty:

Thank you. Thank you for having me and thank you to Sharsheret and Peggy and everyone for all the great work that you guys are doing. I will try and make this as concise as I can. My journey started back in 2010 when my sister was diagnosed with Stage I breast cancer and at that time was tested for the BRCA mutations. When she became positive, the rest of the family did do the testing and I found out that I had the BRCA2 mutation and started on my screening and preventative journey. Had my ovaries removed at the age of 45 and was doing breast MRI and mammograms. And even to hone in on the research, as the years had gone on, that mammogram became a CT mammogram, which was able to give them much clearer pictures, and I think that only became possible through research and studies of showing that.

Betty:

Fast forward to 2020. Unfortunately, my sister was diagnosed with Stage IV cancer of unknown primary after finishing 10 years of her aromatase inhibitors. It just sort of came out of left field and we remember them sending her tissue samples from the various parts that had become positive to another institution to look for certain attributes. Even four years ago, they weren't doing even as much as we are now, knowing targeted tissue sampling and being able to use that to see which immunology techniques could possibly be utilized.

Betty:

Unfortunately for her, nothing came out as something that they knew about a targeted therapy, but they did use Lynparza because that was something for the BRCA mutation family that had been shown to work for people with a Stage III or IV. Usually it was breast cancer, ovarian cancer, some pancreatic, prostate, that kind of thing. And it did work for decreasing the numbers in terms of her CA125 and clinically. Unfortunately, it didn't help that much with physiologically, and she did end up passing away in December of 2020.

Betty:

Fast-forward two months, I came back from helping her in Dallas, Texas and I had my mammogram in December and I had an MRI in March and that came back something suspicious. It took about three weeks to get a biopsy at that point, and it did show to be DCIS, which I was sort of waiting for that shoe to drop. I had always planned on having a double mastectomy. I felt that knowledge was power and wanted to avoid cancer and treatment if I possibly could. But life just gets in the way, COVID happened, and things come to a halt. So I amassed a team and I called Sharsheret in that timeframe and spoke to people through their program, which was so helpful, and actually found out that there was a newer surgery these days that when you wanted to do autologous tissue placement, they called it DIEP flap reconstruction. That was the DIEP.

Betty:

And found a team and for that kind of surgery, they do a specific test called a CT angiogram, and that enables them to see the different types of arteries and veins that they're going to be using to transplant that abdominal tissue and make breasts out of them. It's unbelievable when you think about it. So about two weeks before my surgery, I go, this is April now, I go in for this test and I come back. Everything was fine with that. As I was pulling into my driveway, the My Chart dings ... and it also goes through just the systems, your lungs, bones, and pancreas is on there. And lo and behold, the head of my pancreas was bright, which is what you want to see on an angiogram, that there's blood flow, but the body to tail was dark. No one quite knew exactly what that meant. But I was at a very large teaching institution in New York City and I was very lucky that they said very quickly, "Well, I'm not sure what's going on, but maybe you should talk to our pancreatic specialist."

Betty:

The plastic surgeon said, "I'm not sure what's going on, but maybe you should have an endoscopic ultrasound." A little bit more specific test for the pancreas itself that isn't seen on a regular endoscopy. So in a matter of about two weeks, I was able to do both of those things and I was found to have a three centimeter pancreatic mass, all the while knowing that pancreatic cancer was part of the BRCA family of cancers that happened, but we really didn't have any family history and I hadn't really thought about that. And even at that time, I don't think that they were encouraging people with the BRCA mutation with no family history to go into surveillance at that time. So this came as quite a shock as you can imagine. The breast cancer had to go on hold and in a matter of a week, I had a port put in and started out on my course of treatment.

Betty:

I will say that I was very fortunate that I did know already that I had the BRCA2 mutation because of all the research that they have done already. The type of chemotherapy that I started on was FOLFIRINOX. And through clinical trials and studies, the oncologist reassured us that they have seen patients with Stage IV pancreatic cancer getting FOLFIRINOX, and if they had been BRCA2 mutation carriers that they were walking and talking and doing amazing. And my tumor was really not Stage IV, it was Stage IIB, I found out with the surgery, but that was really very fortunate, because fast-forward a few years now of talking to thousands of people through all different groups and everything, it takes a long time, first to get the genetic testing and then to figure out which type of chemo to do. And you're losing very precious time, especially with pancreatic cancer, to get that going very quickly.

Betty:

So all the research that had been done prior and clinical trials that people had gone through, I benefited from and knowing that that was the type of chemo that I should get through. I had seven rounds before I had a partial pancreatectomy and splenectomy because of where the tumor was I did not need a Whipple. And then I had five treatments afterwards and at that point there was no evidence of disease. And that was fast-forward to November of 2021, and that's when the oncologist came to see us that one of those last appointments and said, "Would you be willing to enter a clinical trial with us? There is a trial out of the University of Pennsylvania that is looking at ..."

Betty:

As I said before, it has been well known for many years that a Stage III or IV cancer as part of maintenance Lynparza has done very, very, very well, and people will be put on that right away. But the question is whether Stage I or II would also benefit from being on this medication. And of course as the patient, I would've taken it no problem, but it's not FDA approved for that, it's thousands and thousands and thousands of dollars a month, but that they are doing this study.

Betty:

And what I had found out is that there's only about 200 people across the United States that were eligible for this study about per year. I had to be a BRCA1 or 2 mutation carrier that had Stage I or II pancreatic cancer that it was able to be resected, and that currently is no evidence of disease. And that I had finished the first line treatment of the FOLFIRINOX. It meant this trial, called the APOLLO trial was a year worth of taking ... it was a randomized controlled study, so there were two arms of it, a placebo and taking the medication, and I wouldn't know which arm that I was in.

Betty:

And it meant coming back to the institution every month for checkup blood work, and every three months was a CT scan. So as most cancer survivors will tell you, that having a little extra someone looking at you and coming into the hospital to have that isn't necessarily a bad thing. I jumped on the chance. To me survivorship and being let go is a little scary. So this was a chance to be watched a little bit more closely, but I would've been having the scans anyway every three months. But the research team would come in and ask if I was having any signs or symptoms untoward and they mark down everything. I had a log that I had to keep of every medication timing that I had done, and I would hand that in. And this was not something that you just get from CVS, it's a research pharmacy that this institution had.

Betty:

So it was as if I was going through chemo. I didn't get any medication IV-wise, but I would sit in the same room and waiting for this medication to come from the pharmacy and then I would go on my way for the next month. So this was only a year, and because of how few people fit into this category, it's going to take a while to finish this program. But I really felt that it was so important, even though I wouldn't know which arm that I was in, I still felt that it was so beneficial to be able to advance science and for the people that would be coming behind me and to be able to use this medication if it was something that they end up finding out is something that would be helpful for that.

Betty:

I remember asking at almost every appointment, is there something new on the horizon? Have you found anything new that would be helpful? Or should we be looking into a clinical trial? And the answer was never, no. It was just, we usually will look at these things at a juncture of whether something stops working, then we will look to see what trials and things would be helpful or at some various junctures. So luckily, my numbers at the time kept going down and down and down. The tumor was shrinking and shrinking. So during the treatment, I wasn't really a candidate for that, but I really felt very fortunate that I was able to participate in some way.

Betty:

And although I will never know, and hopefully I won't know, because I had actually asked at the lead of this study, "Oh, I'm finishing in December, will I be able to find out if I got it or not?" And she said, "No. The only way you'll actually be able to find out is if I do have a recurrence." Then they unblind it. So that I would know if I had it or not. So I'm okay with not knowing right now.

Moderator:

You know what that makes a lot of sense, Betty. Your story has so many aspects we're going to talk about tonight. Thank you so much for sharing.

Betty:

Thank you.

Moderator:

We're so grateful for you to share your story. Okay. So tonight's primary speaker is our very own Peggy Cottrell. Many of you already know Peggy who serves as Sharsheret's genetics program manager. She's a graduate of Sarah Lawrence College Master of Science in Genetic Counseling Program. And at Sharsheret, Peggy consults with women and families and answers individual questions about family history, hereditary cancer mutations, personal risk, and she contributes to the development and implementation of Sharsheret's hereditary cancer resources and programs. Peggy, the screen is yours.

Peggy Cottrell:

Hi, welcome, tonight. I'm going to go ahead and share my screen and get started with the main presentation here. Let's see if I can ... there we go.

Peggy Cottrell:

Okay, so I want to do a quick review about genetics to start with. So it wouldn't be a Sharsheret genetics presentation if we didn't mention that one in 40 individuals with Ashkenazi Jewish ancestry carry a mutation in either BRCA1 or BRCA2. And so it's important especially for those with Ashkenazi ancestry to consider testing even in the absence of family history. There are large numbers of people who test positive even though there's no one in their family who's ever had cancer. Now everyone who carries a cancer gene mutation has a 50% chance of passing it on to the next generation regardless of gender. And so it's important for men and women to be aware that this is something they need to think about.

Peggy Cottrell:

Nowadays, we think about lots of other genes other than BRCA1 and BRCA2 when we do testing. And there are now broad multi-gene panel tests that are available. If you were tested for only BRCA1 and BRCA2 years ago, it might be worthwhile finding out if a panel test makes sense for you. Most of the testing that's done nowadays is done as a panel. Now, if the results of genetic testing are still negative, it's important to realize that the cancer could still be inherited. Very often people with negative results, but a strong pattern of cancer in their family, will continue to have careful screening. And finally, it's so important to note that all the genes that are on these hereditary cancer panels are actionable, which means that if you test positive, you have the opportunity to choose to do something different, which could be very important in managing your health and possibly saving your life.

Peggy Cottrell:

With that out of the way, we're going to move on to talking about research. And I want to share that we have content on our web page about all of these studies, and we come to get this content because of a partnership that we have with FORCE. And Diane is going to tell us a little bit more later on about how they collect these studies. But we partner with them to syndicate these studies onto our own web page. And we're going to be posting in the chat the link to this page, which you can find pretty easily on our website. And if you're interested in finding out more about research, you can take a look there to find out about some of the studies that are available.

Peggy Cottrell:

So clinical trials help us learn more about cancer, and when you participate in a clinical trial, it gives you access to cutting edge technology. And that's because there are opportunities within still getting the care that you should be there are opportunities that doctors want people to try new things. That might be new screening, it might be new medications. And they're developing new treatment strategies and they need your help to do that. So in some studies, you might be getting a new treatment or you might be getting some kind of closer monitoring than you would have based on what's recommended as standard of care.

Peggy Cottrell:

And I think most importantly, when we think about hereditary conditions, providing knowledge for future generations is a high priority for many of our callers and motivates them to participate in research as well. So I'm going to go through probably about 10 different studies that are available. I'm going to touch on these very, very quickly. Nobody is going to be a good candidate for all of these studies. And many people will not really be a good candidate for any of these studies. But if you think you might be interested in one of these, then it's important that you check with your doctor and find out if this is something that would make sense for you and make sure that everything you do goes with medical advice.

Peggy Cottrell:

So as we share these different studies, we're not saying these are great studies. We're not saying these studies are for you. We're saying these studies might be for you, and please talk to your doctor and figure that out.

Peggy Cottrell:

This is a cancer treatment study and it involves using two different kinds of medication. One being a PARP inhibitor, which is a target for people with BRCA1, BRCA2, and other mutations, along with an immunotherapy drug. And we have a caller who was on a study very similar to this, who had an amazing response to the treatment. And we think that this may be a good treatment approach to start with these medications to knock down a cancer. This study is available looking at those medications.

Peggy Cottrell:

This is another cancer treatment study. And this study is also looking at a PARP inhibitor with another medication, not an immunotherapy, but another unspecified drug, according to this promotion. And this is a study that's again open to people with cancer because this is a cancer treatment study.

Peggy Cottrell:

So what about if you don't have cancer? Are there studies that are available out there for you as well? And this very interesting study is probably available to almost all of us on this call. This is a study that's trying to learn more about how genes outside of BRCA1 and BRCA2 and some of the other big genes that we know about, how do they impact breast cancer risk? It's pretty easy to enroll in. You send in a saliva sample. Anyone 18 years or older living in the United States is eligible and a diagnosis of cancer is not required.

Peggy Cottrell:

This is another approach. This actually could be done by someone who is a breast cancer survivor, but this is for specifically people with a BRCA1 mutation who haven't yet had their ovaries or tubes removed, would think about having just the tubes removed first at a younger age and then keeping the ovaries until closer to the age of menopause. And there are a couple studies out that are looking at this as a possibility. The main fabulous thing is that when you take out the tubes, the only thing it stops is the meeting of the egg and the sperm for getting pregnant. And so you can remove just the tubes without going through menopause, and that could be a big advantage.

Peggy Cottrell:

We know that many times ovarian cancer actually starts in the fallopian tubes and many doctors are actually already taking this approach with women. But it's important if you're going to take this option to do it as part of a study. And that's because we don't have any published evidence yet to say that this is an effective approach to take. Now this study is only with BRCA1, and that's because BRCA1 has the highest risk for ovarian cancer. But there's a different study that's very similar but actually allows people to have other inherited mutations that increase ovarian cancer risk. And so these are studies that you could absolutely look into.

Peggy Cottrell:

Sometimes there are studies that are mainly looking at how people feel about things. And it's important to figure out what patients are thinking because that helps doctors and genetic counselors know how to approach these problems. Very often when women have inherited mutations, it can impact their ability to get good screening, because they may be pregnant and you can't have breast cancer screening when you're pregnant, or even when you're breastfeeding because those processes make the breasts very busy and it can interfere with the ability to be able to read those studies effectively.

Peggy Cottrell:

And so researchers are interested in finding out from women who have tested positive, how they made decisions about the timing of pregnancy, of breastfeeding, of breast cancer screening, and finally of risk-reducing surgery. And we have many callers who have concerns in this area. Some women want to have a large family, and it can mean that they may be going from pregnancy to breastfeeding to pregnancy to breastfeeding, and not having a lot of time in between for their breast cancer screening. So important information to understand.

Peggy Cottrell:

What about building a family after cancer? So this is a study that's trying to evaluate tools that would educate young cancer survivors about their fertility options. Again, this is something that is not a medication or a procedure, but it's just trying to understand the best way to educate women about these issues.

Peggy Cottrell:

Vaccines are a really up and coming way that we hope to be able to reduce the risk of cancer in people with hereditary mutations. We tend to think of vaccines as being related to infections, but it turns out there are certain common pathways by which cancer develops. And so there are ways to use a vaccine to target those particular chemicals. There are a bunch of different vaccines that are being studied and they're studying, first of all, to make sure that the vaccine is safe and that it doesn't have large side effects and also long-term following of people who receive the vaccine to see if it reduces the risk of cancer. These studies need to recruit a lot more people in order to be able to evaluate the effectiveness. And so this could be an important thing to consider. Nobody's published any studies yet about vaccines. We're really still at the very beginning and it will take some time to be able to prove any kind of effectiveness. This one is for people with BRCA1 and BRCA2 mutations.

Peggy Cottrell:

This is a different vaccine study that looks at cancer prevention and Lynch syndrome. Now, Lynch syndrome is an inherited cancer predisposition that increases the risk of colon and other cancers including uterine cancer, ovarian cancer, and other cancers of the GI tract. There are five different genes that are associated with Lynch syndrome. And this is a totally different vaccine that's going to target different chemicals that are part of the process of the development of these cancers in people with Lynch syndrome. And so this is again another area where doctors are trying to understand this process.

Peggy Cottrell:

This is a screening study. And in screening studies we're trying to find ways to detect cancer early. And pancreatic cancer has been a cancer that has been hard to find early. One of the things that we're going to talk about at the end when we talk about updates is that there are studies that have been published now that are finding that pancreatic cancer screening can make sense for people who carry mutations that put them at high risk to develop pancreatic cancer. And you can see some of those mutations on the list here. What this study is trying to do is in people with an increased risk when they undergo these screenings, which involve an endoscopic ultrasound and a specialized MRI, the goal here is to try to study some biomarkers that might either be derived from images or from tissue samples to see if there is some additional way to improve the early detection of pancreatic cancer or finding these kind of pre-cancerous lesions.

Peggy Cottrell:

This is another example of looking at other factors that can be increasing risk for cancer in those with hereditary breast and ovarian cancer. We know that BRCA1 and BRCA2 and PALB2 significantly increase the risk for breast cancer and ovarian cancer, but we know that there are other factors that impact that risk. Sometimes these are other genetic factors that people are carrying and other time they are non-genetic things. So certain lifestyle factors or exposures that may happen over time. And so in this study, those who are enrolled are going to share information about their lifestyle habits and exposures and also provide a sample so that that further testing of genetics can be done to try to determine a way that we can say some people with these mutations might have a higher risk to develop cancer compared to other people, and we may be able to figure out how to answer that question.

Peggy Cottrell:

So this is a registry. And a registry is where if you have an inherited mutation, you can sign up to belong to a listing of people who have inherited mutations. And the doctors who curate this list help deliver up-to-date information about managing cancer risks, and they provide resources to these families to help make sure that they're getting the best care. In exchange they also may study samples from these people to see if they can learn anything additional about hereditary cancer.

Peggy Cottrell:

This is a study related to Lynch syndrome. And with Lynch syndrome people a colonoscopy on a much more regular basis. This study is looking at collecting stool samples and using a multi-target DNA test on the stool to see if there's a way to find markers that would point out the early onset of colorectal cancer.

Peggy Cottrell:

And finally, to finish up, I want one study that concentrates on men, those with a prostate. There are a number of genes, and you can see the list here, that can increase the risk for prostate cancer. And the NIH is running a study that involves screening MRI of the prostate every two years with a biopsy if the MRI is normal. Now, typically an MRI of the prostate is not a part of screening, and so this study is trying to just determine if that would be an effective approach for screening high-risk men for prostate cancer.

Peggy Cottrell:

A couple of reminders about research. Always important to collaborate with your own team and ask them for advice about what's going to make the most sense for you. If you want to participate in the study and if you find something on our list that seems to be appealing to you, you can print up the information about that study and bring it with you to your doctor's office and talk with your doctor about whether you think this is a good idea.

Peggy Cottrell:

Sometimes if you're going to participate in a study, it involves switching the facility or the physician that you're being treated by. And there are pros and cons to that. Many times, large studies have multiple sites, so people all around the country can participate in these studies. And it's always important if you're going to participate in a study to be aware of the technicalities. There are rules and pros and cons that go along with all of these, and it's important to get the help of your doctor to read the fine print and make sure that this is something that's going to make sense for you.

Peggy Cottrell:

I want to finish up by talking about 2024 updates in genetics. And this is something we always like to do on our genetics webinar. And one of the big changes that happened this year is related to CHEK2. And people who are carriers of a CHEK2 mutation have in the past been told that they need to pursue a higher level of colon cancer screening, because they were at a significantly increased risk of colon cancer. Perhaps twice the normal risk. And the NCCN guidelines, and that's the national organization that sets guidelines, is pulling back on that and realizing that the risk for colon cancer is probably not as high as they originally thought and now they're recommending that colon cancer screening be begun at 45 as in the general population unless there's a history of colon cancer in the family at younger ages. Again, something to talk about with your doctor.

Peggy Cottrell:

Pancreatic cancer screening studies continue to show that screening starting around age 50, variable from one gene to another, but around age 50, with the endoscopic ultrasound along with the specialized MRI called an MRCP, is effective for finding pancreatic cancer at a stage when it can be treated. So this is again important to know.

Peggy Cottrell:

The population risk for ovarian cancer is going down. And I thought the number was one in 87 and I was double checking the number on the American Cancer Society webpage just about a week or two ago, and they're now saying one in 91. We used to say one in 70 or one in 72. Now, the reason why ovarian cancer is going down is twofold. One is more people taking oral contraceptives. And oral contraceptives, while they may slightly increase the risk of breast cancer, they pretty significantly decrease the risk of ovarian cancer.

Peggy Cottrell:

Also, there are fewer individuals taking hormone replacement after menopause, and both of these have combined to bring that number down, and that is good news. However, what is probably less good news is that we continue to see an increasing risk for cancer in those under 50 that was not there in previous generations. And scientists don't know yet why we're seeing more cancer in those who are of younger generations. They have some different theories. It's not proven yet, but it's important for everyone to continue to be careful about their screening. Thank you so much for listening to my presentation and we can move on to questions.

Moderator:

Thank you so much, Peggy. We're also going to bring ... I am pulling her up now. Add spotlight. Okay. We're also going to bring Diane Rose onto the screen. Diane, as I mentioned earlier, is the VP of Research at FORCE, which stands for Facing Our Risk of Cancer Empowered. FORCE is a national non-profit that improves the lives of millions of individuals and families facing hereditary cancer and Sharsheret and FORCE have a long history of partnership. Diane has over a decade of advocacy experience and currently serves on many committees including the NRG Oncology Patient Advocate Committee, the Oncology Cancer Prevention and Control Committee, and the Oncology Breast Committee providing review and input into study concepts and protocols.

Moderator:

She also serves on the working group at the Metastatic Breast Cancer Alliance. Diane leads FORCE's collaborations with researchers to facilitate two-way communication between researchers and the community they are studying. Diane, thank you so much for being with us to answer some questions about studies tonight. We got a lot of really, really wonderful questions and so we're just going to go back and forth.

Moderator:

I'm going to start actually with Peggy for a very baseline question, which is, can you speak to the timeline of genetic testing? Once a sample is shipped to the lab, generally how long until the patient knows the results? Does it take longer to learn if the results are positive? In other words, do they do additional testing before they get back to you? And who gets those results? Is it the healthcare provider? The patient? And what does one do when one gets those results?

Peggy Cottrell:

Results nowadays usually take somewhere between two and three weeks to come back once the lab has the sample. And it generally takes about the same amount of time whether the result is positive or negative. Sometimes if they find something uncertain, they may have to look through and try to figure something out, but in my experience it's going to be pretty similar, regardless. Who gets the result first is going to depend on the lab and the way the test was ordered. So if you go through a genetic counselor or your doctor, then that healthcare provider is going to get the result first and will share it over with you.

Peggy Cottrell:

However, things have changed with medical records and sometimes there are laws that once a result is in, it's going to go into your electronic medical record and you may end up seeing it before your doctor or your genetic counselor does, and that's important to be aware of.

Moderator:

Okay, thank you for that. Diane, we have received so many questions as part of registration and even in the chat tonight about how to find clinical trials. So can you take just a moment or two to explain about FORCE's clinical trial finder?

Diane Rose:

Absolutely. And I just want to thank you so much for inviting me to participate and to help answer these questions, because as Peggy mentioned, research really is the answer not only for ourselves but for future generations. So very quickly, FORCE curates these studies for our community on our website and through our partners in two ways.

Diane Rose:

One is directly working with researchers who reach out to us for our assistance. So whether that's from myself and other FORCE staff or from our trained research advocates, to help through really the whole continuum of the research process. It might be developing a survey for the community. It might be developing protocol or the concept or ideas for a study. So we work directly with the researchers.

Diane Rose:

And then another way that we curate these studies is by directly going to clinicaltrials.gov and searching for studies that are for the hereditary cancer community. We use their search query and we pull the list and there's hundreds and hundreds of studies, and then we prioritize those. Which ones do we think are high priority for our community? Things that our community is asking us for more research information on. And so that's how we pull these studies onto our website. And then therefore, once it's on our website, our partners like yourselves can share it on your website with your community.

Moderator:

Exactly. And if we could put that link once more into the chat box, that would be amazing. Although we'll send it out several times, but you can find exactly what Diane is speaking about on the Sharsheret website and it's designed that way. Like you said, there are hundreds of these trials, so how do you decide which ones go on your finder?

Diane Rose:

So we try to get as many as we can onto the finder. It takes a long time, probably about 40 hours of work to interpret what is on clinicaltrials.gov. It's not necessarily a patient-friendly site. It's mostly for clinicians to read and understand. And so our team takes the time to read through the studies, understand them. We have certain criteria. We use a rubric to make sure that we're finding studies of high priority. So we might look for studies that are offered across the United States, not just at one single site in a state, because then more people can have access to the study.

Diane Rose:

We look for a combination of prevention and treatment and quality of life studies to make sure we have a wide variety of studies there. And then certainly if what we hear in the news, we want to make sure that we're bringing those studies forward because it's front and center for people and we want to make sure that we have that information up on the site.

Moderator:

Thank you. Like you said, you look for treatment and quality of life and prevention, and that really echoes what Peggy was saying as well, that some of these things you wouldn't expect to be considered research or clinical trials, but they actually are. And there are a lot of ways to help that go well beyond treatment trials, which I think is an amazing point. We're hammering home tonight. Okay, there are many more questions. Here's one. What are the preventative or are there additional preventative measures aside from prophylactic surgery and regular checkups for hereditary cancers for people with mutations that are on trial now and might be expected to come out in the next decade or so?

Peggy Cottrell:

Yes. So I think one that we have a lot of hope for is vaccines. That it will be possible to use that. There was a study that I didn't talk about tonight because it's not recruiting anymore, but it uses a medication called denosumab, which is actually an osteoporosis drug, to possibly reduce the risk of cancer. That's being studied. That trial is no longer recruiting new people, so it's moving forward and hopefully there will be some information about that. Again, a well-known commonly used medication that may be a good tool. So those are just a couple of the things that are out there.

Moderator:

Following up on what you just said and your mention of vaccines, somebody asked, and what a great question this is, is anybody currently researching a way to remove or repair these mutations in somebody who's already known to be carrying them? We know that there are ways to not pass them on through PGTM and things like that, but what about for somebody who already has that? Is anybody researching this?

Peggy Cottrell:

Yes, absolutely. I don't know if anybody's researching it for BRCA1 and 2 because hereditary cancer is a little bit more complicated. And again, we would have to have a technology to remove this mutation from all of the cells that would be at risk. And are we talking about all the cells in the breast, all the cells in the ovary, the cells in the pancreas? So it's complicated.

Peggy Cottrell:

But I do want to say I was at a genetics conference this year where they were talking about using this CRISPR technology to take mutations away in sickle cell. And there has been some success there. Now again, when you're dealing with blood, it's a little bit easier and the type of mutation a little bit easier, but this is the beginning of what we can hope for at some point in the future, whether ... I don't think in our lifetimes we'll see this kind of treatment for BRCA1 and 2.

Although my life, I'm further along, so maybe in some very young people's lifetime we'll see some of these things.

Moderator:

Thank you. Okay, we have time for just a small handful of more questions. And a couple people asked, can you speak briefly to the other risks for carriers of mutation in addition to cancer diagnosis? So some of the things that came up are if you carry a mutation, might being pregnant increase your risk of a diagnosis? Or does a mutation impact fertility at all? Are there any other non-cancer risks when you carry a mutation? I'm sure it varies, so just in general.

Peggy Cottrell:

I think in general with BRCA, pregnancy is not considered to be a risk, and when people are pregnant more, it may actually reduce their risk for cancer. However, if a small cancer is there when you become pregnant, then the hormones of pregnancy can lead to that cancer growing more quickly. That's sort of a mixed, I guess. There are some studies that seem to suggest that for some people being a BRCA carrier does reduce fertility and that would be related to ovarian reserve. But I think that's not true for everybody. But it's something to be aware of. It can impact some people. But as far as BRCA1 and 2, I don't know of any other risks outside of the cancer realm of any significance.

Moderator:

Thank you. Diane, a couple of questions about trials before we close up. One is very specific. When someone has a more rare mutation BRCA1 or something like that, are there also studies for them? Or that they can join that are more general studies or more specifically targeting those mutations?

Diane Rose:

The answer to both of those questions is yes. So there are overall general studies, especially for prevention and quality of life. The surveys and the registries that Peggy mentioned, those would be available for people who have the rare mutations. But then we also do have specific studies just for people who carry that very specific mutation.

Moderator:

Okay. And they can, like all these others, be found on the finder.

Diane Rose:

Yes.

Moderator:

And then I wish we had time for more, but let's finish off with this one, because I think advocating for oneself is so important. The question came in, what should someone do if their doctor doesn't mention clinical trials but they are interested in learning more?

Diane Rose:

I would recommend that the patient ask their doctor outright. There could be a reason why the doctor hasn't mentioned clinical trials. And so it's important, as you said, to advocate for yourself. And just ask the doctor, "I'm interested in clinical trials. Is there anything that you have here at your facility that you would recommend or any other studies that you're aware of that you would recommend for my situation?" And if not, then there are tools out there that you can look for, search for studies, and then take that information again back to your physician and see if it is something that they would be able to guide you through.

Moderator:

Thank you. Thank you both so much for answering these questions. I wish we had time for more. And I do want to acknowledge that we do get several questions that we're really more geared toward MDs, specifically about treatment protocols and things like that. And that because we don't offer medical advice, that's why those questions weren't asked.

Moderator:

And if there are any more questions, not only are our genetic counselors at Sharsheret happy to answer any questions about screening or clinical trials, but I'm sure ... I didn't ask her ahead of time, but I'm pretty sure Diane would also be happy to mention that. So I'm going to take the spotlight off of you so that you can relax a little bit as we conclude. Okay. So I want to thank Betty for sharing her story, and to Peggy and Diane for sharing both of your expertise with us this evening.

Moderator:

It's always wonderful to hear about the progress and innovations being made. I want to remind you that Sharsheret has some wonderful educational support resources available to you. We have a booklet entitled Your Jewish Genes, which discusses not only BRCA but other hereditary cancer mutations and is really appropriate for anyone who has a mutation or is concerned about their risk. One of Sharsheret's best-kept secrets is that our genetic counselors offer family conference calls. This allows members of your family, no matter where they are located, to understand their personal risks, to learn proactive steps they can consider, and as with everything else Sharsheret offers, this is a free resource.

Moderator:

You can find FORCE's syndicated content outlining clinical trials on the Sharsheret website. This allows people to find cancer prevention, treatment, and quality of life studies enrolling people with or at high risk for hereditary cancers. And that link is once again going in the chat box. You'll have the opportunity to download or order print copies of Your Jewish Genes and other relevant pieces through the follow-up e-blast, which you'll receive later this week or at the very start of next week. And you'll have a chance to request a family conference call or a personal call with one of our genetic counselors in the evaluation of tonight's program, as well as the follow-up email. And speaking of evaluations, please take a moment to fill out a brief evaluation survey on today's program. The link just went into the chat box.

Moderator:

Before we conclude, I want to let you know about two upcoming webinars. On Thursday, February 13th at 8:00 PM Eastern/ 5:00 PM Pacific, a webinar on GLP-1 weight loss drugs and breast cancer, specifically. The link to register for that is in the chat box now. We also have a webinar coming up on Monday, February 24th. The topic of this one is Advancing Breast Cancer and Ovarian Cancer Research in Israel: Latest Discoveries and Innovations. This one is actually going to take place during the day at 1:00 PM Eastern time, which is of course 8:00 PM Israel time. And the link to register for that one will be available on our website in the next day or so. And if you can't do it during the day, you can always register and you will receive, just like with all of our webinars, a link to the recording shortly thereafter.

Moderator:

Once again, I want to thank all of our speakers tonight, as well as AstraZeneca, Pfizer, the Basser Center for BRCA, and of course, FORCE for their partnership tonight and in so many other initiatives. And please remember that Sharsheret is here for you and your loved ones during this time. Sharsheret provides emotional support, mental health counseling, and other programs designed to help you navigate through a cancer or pre-cancer experience. All are free and completely confidential, and you can reach us at the email in the chat box now. Simply clinicalstaff@sharsheret.org. Thank you for joining us and have a wonderful evening. Good night.