

The Orange County Jewish Cancer Education Initiative

Jewish Ethics and Genetics

National Webinar Transcript

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Presented by:



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Jewish Ethics and Genetics

Jessica Jablon:

I'm Jessica Jablon. I'm the California Regional Director of Sharsheret. Thank you so much for joining us on your Thursday night to discuss the intersection between Jewish ethics and cancer screening. Before we begin, I want to thank our generous sponsors. We received a City of Hope Kindness Grant, which is allowing us to put on this program. And this is the first in a series of three events called the Orange County Jewish Cancer Education Initiative geared towards educating the Orange County California community about hereditary risk. I know a lot of you are not from Orange County and we're really excited that you're here with us tonight as well. I would also like to thank Merck for their generous sponsorship and our community partners at Temple B'nai Israel in Tustin, Merage JCC in Irvine, and the Orange County Jewish Community Scholar Program or CSP for partnering with us on this meaningful program.

We also want to thank the many Orange County area synagogues who promoted this event within their communities. Before we get into the program, just a few housekeeping items. Today's webinar is being recorded. Participants' faces and names will not be in the recording. If you would like to remain private throughout the webinar, you can turn off your video and rename yourself or you can call into the webinar and instructions are in the chat box now for both options. You may have noticed that all participants were muted upon entry. Please keep yourself on mute throughout the call. If you have questions, put them in the chat box either publicly or you can click on Sharsheret in the chat box to submit a private question. As we move into the program itself, I'd like to remind you that Sharsheret is a national not-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures.

The information provided by Sharsheret is not a substitute for medical advice or treatment for specific medical conditions. You should not use this information to diagnose or treat a health problem. If you have any questions that are specific to your medical care, we recommend that you speak directly to your medical provider. Always seek the advice of your physician or qualified health provider with any questions you may have regarding a medical condition. Now that we've covered that, we are going to be hearing from some incredible speakers tonight who will discuss genetics and the increased risk in the Jewish community, some signs and symptoms to be aware of, screening recommendations, what we need to know and share with our doctors, and what Jewish law says about taking care of ourselves. I'm also excited about the opportunity to briefly share Sharsheret with all of you.

Sharsheret is Hebrew for chain and we're a national Jewish nonprofit organization that helps all of those facing, living with or at increased genetic risk for breast or ovarian cancer. We provide free and confidential genetic and mental health counseling, emotional support, financial subsidies, and life-saving education to people of all backgrounds. Our support services are designed to help navigate you through the cancer experience. We also partner with synagogues, hospitals, healthcare professionals, campuses, volunteers and organizations to educate and empower people to take care of their health, know what questions to ask, and to understand their risk. And that's what we're doing here tonight. So, after introducing our panel, we will hear from each of our speakers and then we will open it up for questions. If you have a question, please put it in the chat box and we will do our best to answer as many as we can after our panelists share their presentation.

I'm honored to introduce our esteemed panelists this evening. Christina Rybak is a licensed, board-certified genetic counselor specializing in cancer genetics. She received her master's degree in genetic counseling from the University of South Carolina and her bachelor's degree in English from Duke University. She joined City of Hope's division of clinical cancer genomics in 2014, where she provides genetic counseling and cancer genetic risk assessments as a senior genetic counselor by video and in person at the Orange County Lennar Foundation Cancer

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Center in Irvine. In addition to patient care, she's a faculty member of the City of Hope intensive course in cancer risk assessment. Christina also works closely with the Precision Medicine Project for research and clinical care. Her research interests include hereditary gastrointestinal cancers and incidental findings on genetic testing. She is an active member of the National Society of Genetic Counselors and American College of Medical Genetics and Genomics.

Our next panelist is Dr. Josh Cohen, and he is a board-certified gynecologic oncologist, a medical director of the Gynecologic Cancer Program at the Lennar Foundation Cancer Center at City of Hope Orange County. Dr. Cohen is an expert in the surgical cytoreduction of cancer and in the use of minimally invasive surgical techniques including robotic surgery. He completed a fellowship in gynecologic oncology at UCLA and Cedars-Sinai Medical Center and has been recognized by Los Angeles Magazine as one of LA's Top Doctors and as Southern California Super Doctor. Dr. Cohen has led significant efforts in gynecologic cancer research and completed the clinical research training program at the National Institutes of Health, as well as the Clinical and Translational Science Institute certificate program at UCLA Medical Center. Dr. Cohen grew up in Orange County and he considers it an honor to serve patients in the same area where he was raised. He has worked with Sharsheret for the past five years and is grateful for the immense work that Sharsheret continues to do with patients and families impacted by breast and ovarian cancer.

Our final panelist is Rabbi Dr. Jason Weiner, who serves as the senior rabbi and executive director of the spiritual care department at Cedars-Sinai in Los Angeles, where he's responsible for the chaplaincy team and all aspects of spiritual care throughout the health system. Rabbi Weiner previously served as the assistant rabbi at Young Israel of Century City. He has earned two rabbinic ordinations as well as a doctorate in clinical bioethics from Loyola University in Chicago where he earned a master's degree in bioethics and health policy. In addition to a master's degree in Jewish history from Yeshiva University. He is the board-certified chaplain through Neshama, the Association of Jewish Chaplains. Rabbi Weiner is a member of the executive committee of the Cedars-Sinai Bioethics Committee.

He is past president of the Southern California Board of Rabbis and has been honored with Rabbinic leadership Awards from the Orthodox Union and Kai Lifeline. He's also the rabbi of Knesset Israel Synagogue of Beverlywood, and he frequently serves a scholar in residence at conferences in synagogues throughout the nation. In addition, he's also the author of three books and has published more than 40 scholarly articles and book chapters as well as several popular pieces.

We're so grateful for all of you to be here tonight and share your expertise with us. Let's get started. Christina, why don't we start with your presentation on hereditary cancer in the Jewish community.

Christina Rybak:

Thank you so much. I'm so excited to be here and to listen to the other speakers. Please just bear with me for a moment while I get everything together with my presentation and putting it up. Just need to share this and I think actually get to the front of the position, so one second here. Does everything look okay to you? No?

Jessica Jablon:

Yes, it looks great.

Christina Rybak:

Okay, perfect. What I'd like to do in just the next few minutes is provide some information about the basics of genetics and inheritance, cause of inherited risk for breast and ovarian cancer, including BRCA1 and 2, which you may be familiar with or have heard something about. But also, expand into how we approach genetic testing today, which does involve assessing your

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risk for other types of cancer and mutations in genes aside from BRCA1 and 2, and some things that you may want to be aware of, particularly as it pertains to the Jewish community.

A couple of things to note. Genes are the blueprints for our bodies. They're really the instructions that tell our bodies how to grow, how to develop. In every cell of our bodies, we have 20,000 genes and hundreds of them influence our risks for cancer. BRCA1 and BRCA2 are just two examples, but they are the most common cause of inherited risk for breast and ovarian cancer. We have two copies of every gene, one we received from our mother, one we received from our father. That's really the basis of having half of our genetic information from each side of the family.

If we focus on BRCA1 and BRCA2, these are really important, partly because they cause significantly increased risks for cancer. Risk for breast cancer for a woman over 60% over her lifetime. Risk for ovarian cancer, depending on the gene between 13 and 59%. For males, the risk for breast cancer is also elevated up to 7% in a lifetime. Depending on the gene, depending on the study, the risk over the lifetime is up to 61% for prostate cancer. Another cancer we think about is pancreatic cancer. And these can be really important things to know about for the sake of screening and prevention.

Why would we want to be focusing on these with relation to the Jewish population? We know that they're of special relevance because of how common it is to carry one of three specific gene mutations in BRCA1 and BRCA2 in Ashkenazi Jewish population. These variations have passed through the population for centuries. In the BRCA genes, about one in 400 people in the general population will have a mutation but one in 40 individuals of Ashkenazi Jewish descent will carry one of those mutations. It's also good to know that the BRCA1 gene mutation called 185delAG, it's not just restricted to individuals of Ashkenazi Jewish ancestry. It has been seen in other Jewish populations. And there are certain BRCA variants that have been seen in the Sephardi and Mizrahi Jewish populations just not at the same level of frequency as with BRCA1 and BRCA2 founder variants.

It is a really low threshold that we use to offer genetic testing to people of Jewish ancestry but we tend to look broadly, so not just focus at on those three gene variants. To look at breast cancer in general, there's really only five to 10% of all breast cancer that's due to a hereditary cause or gene variant running through the family, putting people at increased risk. While BRCA1 and 2 are the most common cause of hereditary breast cancer, there are a whole variety of other genes that have been identified to cause increased risk, and that's what we've learned over the last several decades really since the discovery of BRCA1 and BRCA2. When we think about genetic testing in general, we know that there are genes predisposing to many different cancer risks.

Things like colorectal cancer risk, colorectal polyp risk. This slide shows with the different colors, the genes that predisposed to certain types of cancer. Each gene is associated with its specific cancers. Each gene has varying levels of risk and also specific medical management guidelines. For example, we might find a gene that increases risk for colorectal cancer and someone would be recommended to have tailored guidelines for colonoscopy. Whereas with breast cancer risk, we're thinking of things like increased screening by MRI. I wanted to point out a couple of examples because I think we focus a lot on BRCA1 and BRCA2, but that are relevant to people in the Jewish populations. I put a few circles around a gene called APC. There's a specific variant in this gene called APC I1307K. It's present in one in 12 people of Ashkenazi Jewish ancestry and it increases risk for colorectal cancer. Not to the same level of risk by any means as say, a BRCA gene variant increases risk for breast cancer but it can influence screening guidelines for colonoscopy.

The general approach when someone comes in today would be to offer what we call a multigene panel where we take one blood or DNA sample and we can test for many different

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genes associated with many cancer risks at once. That's something now that is available and it allows us to give the most comprehensive look at someone's cancer risk and make the best tailored medical management guidelines from there. With respect to the ATM and CHEK2 genes, these are genes that predispose to breast cancer. Again, not to the level of BRCA1 and 2 but just in the general population, regardless of your ancestry, approximately one in 100 people will come back with a positive result, which from the genetics perspective is common.

So, it's something that we see in people of all ancestries and can influence a person's screening. Just good things to know about. Why consider genetic testing and counseling? It can influence potentially someone's treatment for cancer. Their screening and medical management. And also, you may be giving a gift to your family in terms of information that has relevance for children. If someone tests positive, all of their children and siblings are at 50% risk to have the same variant. And just the last point to make that genetic counselors are here to really walk through the process with you based on what your values are and the situation in your life to go through with you and talk about the testing that's available and what may be best for you. Thank you. Just wanted to leave it there. Happy to handle any questions that you have.

Jessica Jablon:

Thank you, Christina. If you have any questions for Christina, please put them in the chat and we will get to them after all of the presentations. That was really interesting and we appreciate that. Thank you. Now let's turn it over to Dr. Cohen.

Dr. Josh Cohen:

Okay, great. Thank you also very much for logging in on a Thursday night. I'm going to share my screen here.

Okay. Everybody can see the first line on breast cancer?

Jessica Jablon:

Yes.

Dr. Josh Cohen:

Okay. My name is Dr. Josh Cohen. I'm a member of Congregate Congregation B'nai Israel here in Orange County. Wonderful to be here with you. I grew up in your Yorba Linda, which is Northern Orange County. I know many people are not from Orange County on this call, but just for those who are, thank you for logging in. Christina and I are here to serve and help and lots of other wonderful people to help with cancer risk. Obviously, very passionate about this because every day I treat patients, sadly, who are challenged by ovarian cancer or other gynecologic cancers and breast cancer. In our patient population, Ashkenazi Jews, we have a really unique opportunity to prevent many of these cancers, if there's an inherited risk. To put just something in perspective for what Christina mentioned, there's about 40 people on the call tonight.

If we just take it by numbers, one person on this call definitely has BRCA1 or 2. Their family will forever be impacted by BRCA1 or 2, and that person will save lives if they test positive and communicate that to their family. And that's just on this call tonight. The APC mutation, one in 12. Three of us have an APC mutation on the Zoom call tonight, and that's an increased risk of colon cancer. You'll hear more from Rabbi Weiner about the ethics and genetics with regard to Jewish law. I've personally been referred young women to have risk reducing surgery to remove their ovaries, to reduce the risk of cancer. And they've never heard of the ability to do pregestational diagnosis, meaning that you can actually test embryos for genetic risk of BRCA1 and 2.

There's a whole discussion about that. I don't want to open up Pandora's so to speak, but I just want you to know that this technology exists. Okay. With that being said, breast cancer, really a growing pandemic. And actually, the numbers are increasing locally in Orange County. There's

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about 300,000 women who will be diagnosed with breast cancer in the U.S. this year, sadly. And 43,000 women who will die from breast cancer this year in the U.S., which is way too high. Ovarian cancer is a silent killer. Sadly, 20,000 women will be diagnosed with ovarian cancer this year in the U.S. and 13,000 women will die from ovarian cancer this year, which again is too much. Any person is too much. I've dedicated my career to trying to make this better. Every day there are some sad moments, but there are some happy moments.

Some of those happy moments include patients who have tested positive for BRCA or Lynch syndrome or other genetic predispositions who are then able to undergo risk reducing surgery to prevent cancer from developing. And the best form of treatment is prevention. Sadly, ovarian cancer, we do not have a screening test. We don't have a colonoscopy. We don't have a pap smear like we do for cervical cancer. So, what we're left with are symptom management. And I would tell our participants on this Zoom session today, advocate for yourself and advocate for your family. Symptoms include persistent bloating, abdominal pain, pelvic pain, changes to how you empty your bladder or bowel movements, abnormal vaginal bleeding or vaginal discharge, persistent lower back pain. These are symptoms that we need to take seriously.

We as physicians and allied health professionals, we care about you. We want you to succeed. I will tell you, I'm still looking for a primary care doctor in Orange County. What I found is that the health system here is very strapped, surprisingly. And I think it's good there's more healthcare coming, but sometimes you need to advocate. You need to message your doctor and say, "Hey, look, I'm not feeling well. What's going on? Let's figure this out." If you take away anything from today from me, besides the numbers and some of the genetic risk, I would say advocate for yourself, advocate for your family. It's okay to reach out to your health team and say, "Look, something's wrong. I need help."

If we look at the numbers, ovarian cancer, although it's a fairly rare cancer, it's the fifth leading cause of cancer death in the U.S. for women. Fifth leading cause behind lung, breast, colon, and pancreas. Breast cancer is the second leading cause of cancer death in the U.S. If you look at men, we mentioned prostate cancer for BRCA. We do have wonderful urologists at City of Hope Orange County too who are ready to help, but this is also a leading cause of death for cancer in men. These are common cancers. We have genetic risk that directly increases the risk of these cancers in the Ashkenazi Jewish population as well as certain aspects of the Sephardi population. No one should die from these cancers if we're able to find their genetic predisposition.

I mentioned some of the symptoms of ovarian cancer, abdominal pain and bloating, urinary frequency, changes to bowel habits, irregular periods, postmenopausal bleeding, decreased appetite, pelvic pain, nausea and vomiting, pain with sexual activity. One or two of these, these are things that you would still want to reach out to your doctor. What I tell our patients a day of some abdominal cramping that grows away, I'm not too concerned by, but if you have persistent cramping pain that's not getting better over the course of days to weeks, that's worrisome. That's something that should be evaluated. For breast cancer symptoms, breast pain in any area, any breast lump or nodule, asymmetry of the breast tissue irritation or dimpling of the breast tissue, redness or flaking of skin nipple discharge, change in size of breast tissue, a new lump under the arm that's discovered, or even a pulling sensation along the nipple, those are not normal. What I would encourage you to do is know what's normal for you.

Everybody grows up with different body aspects and different things that they know about themselves. And if there's a little bit of asymmetry that's been there for 40 years, not worrisome. If you're someone who has cramping pelvic pain after eating certain flu foods like gluten, that's okay. But if these are new things that are developing for you and they're not going away, those are things you need to reach out to your primary care doctor or your OBGYN and let us know so we can help. So, know what is normal for you. We have very good guidelines and we have

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people like Christina Rybak who are here to help guide our wonderful members of our congregations and the Jewish community on what the genetic test should be ordered.

One of the most common things I'm asked is, well, I can just do this online, [inaudible 00:22:58]. I got this for my grandson for Hanukkah or my granddaughter, she's going to get tested it. It's not as simple as that because some of these mutations and some of these tests are not high in quality, and some of the data that you get back is not very useful. Sometimes you do yourself a disservice by thinking you've done the right genetic test and haven't actually. There's some really good data that's come out in the last five to 10 years. We were doing BRCA testing for the last 15 years, and I have many patients who are a little older and they say, "Oh, Dr. Cohen, I was tested. I was tested in 2008." Guess what? That test in 2008, not very good. And we actually should retest you. So, it's important to reach out and know that the technology has drastically improved over the last even five to six years where you may benefit from a repeat genetic testing.

City of Hope does an extremely large panel. We're very fortunate. I'm very fortunate that my patients can have genetic testing for free as part of a larger precision medicine study that Christine is involved with. And really, anyone who wants to be seen can have genetic testing for free at City of Hope, Orange County or another location. It's common to do it. I would say you should do it under the guidance of a medical professional to get the best information possible. And video visits are actually easy to do these days.

If you do test positive, there are things we can do. Risk reducing surgery with removal of the ovary and fallopian tubes at a certain age. The term for that is bilateral salpingo-oophorectomy. For breast cancer risk, bilateral mastectomy. There are more genes, as you heard from Christina, than just BRCA1 and 2. Angelina Jolie had BRCA and her mom died from ovarian cancer, sadly. And she underwent risk reducing surgery to prevent that. The other mutations include BRIP1, MLH1, MSH2, MSH6, PALB2, RAD51D and 51C. We actually start these interventions potentially as early as age 35 for BRCA1 patients.

So, genetic testing is important. As you heard from Christina, you inherit genes from your mom and your dad. So, one thing I do often get from men or from women is, well, my mom got tested, so I'm okay. But truth be told, it's actually dad's family who had most of the cancer back on the shtetl. And we don't often talk about the shtetl or what happened to our families, Jewish populations. We don't really know what grandma or grandpa or great-grand or grandpa died from. But actually, it's important for you to talk to your family, and say, hey, mom and dad, what did our uncle passed away from? Well, God forbid. We need to know what people died from because it has implications for your health. If there's a family history of breast cancer, although it may not be your immediate family and your family is from Eastern Europe, whether you think you're Sephardic or Ashkenazi, guess what? You should probably get tested.

Genetic testing is something that... It should not delay cancer treatment. I think that does come up a little bit. Some people have already had a diagnosis of breast cancer, and they say, "Well, I was already diagnosed. It doesn't matter." But it actually does matter because it has implications both for your treatment and for your family. I would say whether sadly you've dealt with breast cancer or not, it still should be an updated genetic testing discussion with your primary care doctor or your OBGYN or your urologist or whoever's caring for you.

I've hinted this a little bit, but there are many different genetic tests. The one that you see on online or read about on Amazon or they send to you for Hanukkah may not be the right test. Know your family history. Ask to see a genetic counselor or physician with a focus or interest in genetic testing. Not all genetic testings are clear. We didn't talk about something called variants of undetermined significance, but there's a lot of power in genetic testing. But there's a lot of uncertainty too. It can be really hard when you order a genetic test and you may be in the gray area. The gray area could be you have a mutation that's not considered harmful, meaning we

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haven't found enough patients who have developed cancer because of it, but it's a rare mutation, meaning that it's not usually found in the general population.

That usually requires an expert to navigate that with you. Someone like Christina who's going to keep an eye on these as they get updated, as we get more patients tested to know if this is truly a harmful mutation or not. That's one of my concerns when people do this at home with just send home kits and have no follow up. These results have implications for you and your family. We can talk more about this. One of the most common questions I'm asked, "If I get tested, can I get in health insurance in the future, if I test positive, positive for mutation? I don't want to get tested because if I'm tested and maybe I can't get health coverage." The answer is that's not the case. Just like someone who's had multiple sclerosis or diabetes or has congestive heart failure, you're always going to be able to have health insurance, at least certainly in the state of California and beyond.

There are rules now with the federal government to protect you. The one thing that comes up is life insurance. And just like anything with life insurance, I think, it depends on the insurer and the plan you're looking at. Obviously, anyone who has certain risks for their life expectancy, that may alter your life insurance. But I think the most important thing is knowing these things for your family and for you, because I would argue preventing your cancer or preventing your family from getting cancer or treating your cancer better is going to be more important than a rate you may get on your life insurance policy, but that's my take. If you test positive for mutation, do you feel comfortable with the treatment plan? It's okay to seek guidance from a place like City of Hope or another expert place like Cedars-Sinai.

It's okay to get that experience at a comprehensive cancer center. Although it sounds scary because it's a comprehensive cancer center, we also treat previvors and survivors, meaning we treat patients who don't have cancer, who have a predisposition. And then we treat patients who have had cancer, who have all the complications of cancer, pelvic organ prolapse, urinary incontinence, City of Hope and places like this, we're set up to treat patients in their entire journey from diagnosis or pre-diagnosis to their treatments after, to their survivorship. It's okay to ask for a second opinion. Your primary care doctor mean well, but if she or he only sees one patient a year with BRCA, they're probably not the person to give you those recommendations. You probably should seek out a specialist. It's okay to ask about fertility preservation.

For maybe our grandmas and grandpas on the phone call, if you have daughters and granddaughters or grandsons, they can see a fertility specialist. And there are many different options for them to collect eggs or embryos and really potentially have a life with children that don't have this mutation. Or maybe they do and they're aware of it, but at least they should hear these options. Take control of your care. If you've had a genetic test, know what's in it, what's in that report, meet with Christina Rybak. Spend 40 minutes going through your genetic history and know what's there, or us or physician like me. Advocate for yourself and your family. Seek out support. Sharsheret is amazing. I'm so lucky and grateful to work with Jessica and Elena and Simone and the whole team. So many of my patients have benefited on their journey from previvorship to diagnosis to survivorship with Sharsheret, with breast and ovarian cancer support.

I'm just grateful to work with this organization as a volunteer on some level, but just always inspired by the things that they continue to do. So, support this organization if you can. They're part of our Jewish community. They're really trying to make a difference in Orange County too, which I really am grateful for. Lastly, it takes a team to treat someone. No one lives in a vacuum. No one lives in isolation. You're not alone. Seek out physicians, seek out your genetic counselors, physician assistants, pharmacists, medical assistants. We're all here for you. We know that healthcare is complex and we know that it can be hard to reach the right person, but if you advocate for yourself, if you reach out to organizations like Sharsheret, you're more often

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than not going to get to the right location. With that, I'm going to stop sharing my screen and we'll have Rabbi Weiner do his presentation.

Jessica Jablon:

Rabbi Weiner, do you want to say something? I do want to just point out one thing real quick, after what Dr. Cohen said, which is that we also, in addition to having wonderful genetic counselors that we work with, like Christina, we have a genetic counselor on staff, Peggy Cottrell, who is amazing. While she doesn't prescribe the genetic testing, she's happy to go through your results with you or if you have questions about whether or not you want to consider it, that is something that we do as well. And you're welcome to call and speak with her. With that, I will turn it over to Rabbi Weiner.

Rabbi Dr. Jason Weiner:

Okay, thank you. It's quite an honor to be here with all of you in such a distinguished panel. I'm also a huge fan of Sharsheret. I've seen personally in my role as a chaplain at Cedars-Sinai, the incredible work that Sharsheret does. And it's really quite an asset to the community and quite a blessing to the community. Also, I'm a fan of City of Hope and of Orange County. I don't live there, but I'm also a fan of Orange County. Anyways. There's really a lot to say. I'll be brief but it's such an important discussion and I just commend all of you for joining for this discussion. And it's a discussion that's been happening in the Jewish community for many, many years. There's a lot of misconceptions, unfortunately. Part of it relates to, people hear rumors. A lot of times Jewish law, Jewish values disseminate through rumors.

Even when things change or adjust or modify, we don't always have great ways of getting the word out about those changes. For example, genetic screening. There was a time when there were rabbis who were very concerned about it. And that was because people didn't understand genetics very well, and there was a lot of stigma and there was also not much that could be done. Even when one would find out what they were a carrier for, there wasn't much they could do about it. So, rabbis were concerned, why test when... What are you going to do anyways? Especially, it's just going to cause stigma and anxiety. How will it help? But gradually they started to see, wow, this could really help. The first major example in the Ashkenazi Jewish community was with Tay-Sachs, which was a devastating illness that many that many Ashkenazi Jews were experiencing. The ability to screen and avoid marriages...

First of all, it brought up a lot of new questions, but it also saved a lot of suffering. There was a rabbi in the Lower East Side, a famous rabbi in the late '70 named Rabbi Moshe Feinstein. When he was asked this question about should we do this testing? He said, "Yes, we should." What's it based on? He said, "It's simple. Not testing is closing your eyes to what you would be able to see." Those were the words he used. It's like closing your eyes to what's right in front of you. It's like crossing the street blindfolded. Why would you do that once you have the opportunity now to do this screening? "It became," he says, "part of basic healthcare."

The Torah says that we're supposed to guard our health. It says *venishmartem meod lenafshoteichem*. You have to guard your health. But it uses that word, *nishmartem meod*, guard your health very much. It's the only commandment in the Torah that has that modifier, very much. You have to go to go out of your way to guard your health. It's not just, oh, it's good if you could be healthy. It's do everything you can to promote your health and wellbeing. This is something that is now a tool. Even though there were some rabbis that at first were nervous about it, this is new, it's scary, is it going to be good? But as they started to realize, wow, this can save lives literally and help so many people, they realized this is part of that *meod* word.

In fact, there's another law in the Torah. The Torah says, *V'asita ma'akeh l'gagecha*. You have to put a guardrail on your roofs. I think in English it's called a parapet, I think. A guardrail on a roof, the type of roof that you can walk on. They lived in these Mediterranean style homes,

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peoples style homes with flat roofs that people would go onto the roof. There was a law in the Torah that you have to have a guardrail there. You can't just take your risk and say, "Oh, who's going to fall off? It's safe." You have to actually have a guardrail on. The rabbi said that was a commandment, not just for that specific guardrail on the roof, it was actually a way of saying that we have to take precautionary measures. Preventative medicine is actually commanded by the Torah in that category of putting a guardrail on our roofs.

And the rabbis realized this is what genetic screening is. This is amazing. It is a tool to help promote health and protect our wellbeing. What started to happen was, first of all, more and more questions arose like when to test, and what happens when you find out you're positive? Some of the questions were like, if a couple is very much in love, should they break off their engagement? When should they be testing? In fact, when Rabbi Feinstein had first permitted in the Jewish community this testing, he came up with a method that he encouraged and some parts of the Jewish community still do it this way, not most. I personally don't necessarily recommend this. But he said, I'm only going to allow it if it's blind, anonymous testing. The way they did it for many, many years, and still in some communities to this day, is that people will get tested and they get a number and then they simply call their number and their potential partner also calls and gives them their number. And they're simply told, are they a match or not? But they're not told the details.

The idea of that was to try to prevent the stigma. But as we became more and more sophisticated with genetic screening, we could do more and more things, as has been mentioned by both of the speakers more questions arose and the desire to have more open testing became relevant. For example, I'll just give two quick examples because they're, I think, important for understanding that debates that happened in the rabbinic community. One was, and this was mentioned before, it was, okay, let's say a couple is very much in love and they now do the screening. Most rabbis, I personally, will not do a wedding unless a couple does genetic screening before their marriage. And I encourage it very, very early. Obviously, they don't usually contact me before they're engaged, but I encourage it right away, especially before when it gets pregnant.

Let's just use an example of a couple that is engaged, madly in love, not yet married, they find out they're both carriers for something. What they're carriers for, this could also have a major influence on the decision, how serious it is, especially as we get more and more ability to test for more and more things. Would you break off a marriage because... I'll give a random example that's not actually genetics. Let's say they're left-handed. Oh, I don't want to have left-handed kids. I'm not marrying you. That would be ridiculous. I don't think there's any genetic screening for left-handedness but I'm just saying that would be extreme. But for the children to not have Tay-Sachs or Huntington's disease, there's lots of different things we could discuss that could change the calculation. Once we had the ability to do PGD as came up before, pre-implantation genetic diagnosis, and you could say, you know what? Even though you're both carriers and you want to have children, you could adopt also, and let's say you want to have children and you're both carriers, you actually could now still get married and have children.

It's just a little bit more complicated. You're going to have to practice birth control and only have children through IVF and PGD. PGD is where the pregnancy takes place through IVF and in the very early stages of the fertilized egg, when it's in the blastocyst stage, very beginning, you have four or five, let's say, of these fertilized eggs. They can just take one cell out of each one and see which one is a carrier for whatever mutation you're trying to avoid and get rid of the ones that are the carriers and just re-implant, get pregnant with the one that's healthy, so to speak. We all have genetic mutations. There's all always going to still going to be something. Then just get pregnant with that one.

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The rabbis were debating, is this allowed? Some of their concerns was like, is this playing God? Is this designer children? What happens if you're trying to avoid, let's say, Tay-Sachs but then the doctor says to you, okay, I have three that don't have Tay-Sachs but do you want to choose which one is taller or shorter or male or female or brown hair? I'm just saying what ifs right now. What if they would start asking more and more questions, that was what the rabbis were worried about. But they said, you know what? No. This is part of healthcare. This is part of basic healthcare and trying to avoid illness. But then other rabbis said, but can you really discard those pre-embryos because those could become human beings. Is that a form of abortion? We know that Judaism allows abortion in many, many cases, but would this be a form of abortion? Would that be a concern?

The rabbis said, actually, it's interesting that the rabbis of the Talmud said many, many years ago, without getting into too many details, but the Torah says an interesting line, (*Bereishis 9:6*) *Shofech dam ha'adam, ba'adam damo yishapech*. One who kills a person, by a person that person may be killed. That's the way you translate that word, that there could be such thing as capital punishment, even though the rabbis limited it. That was what the Torah was saying. But the rabbis of the Talmud said, "It's such a funny phrase, who kills the person in a person?" They said, "Oh, that must be talking about a fetus in the womb." Anyways, we're not talking about abortion yet because anyways, we could talk about it if you wanted, in the question and answer, but Judaism usually allows abortion when necessary. But when they were debating PGD, they said, "Oh wow, this source now provides us with guidance because that embryo, that pre-embryo is not currently in the womb. So, it doesn't even fit into that verse, and therefore it can there's no prohibition against discarding it."

That was a very different view than some other religions took. But that was the way the rabbis analyzed that case and said PGD is allowed. One more case before I'll start to wrap up. It was mentioned already also by Dr. Cohen. The important issue of prophylactic surgeries. A mastectomy would not be problematic by Jewish law. In any surgery you have to ask the question, is surgery allowed? It's a category called *chabala*, damaging. If it's for a purpose, surgery is of course, allowed. It's part of saving life and we believe in *pikuach nefesh*, saving lives. And oophorectomy was a more complicated question because there is a prohibition in Jewish law against what's called *sirus*. That is the prohibition against intentionally causing oneself to become infertile.

I had a case like this when a woman came to me. She says, "I tested positive for BRCA. My doctor suggested an oophorectomy. Is this allowed by Jewish law?" I said, "We need to reach out to your rabbi." This is now going back 15 years already. It was newer then. We reached out to this rabbi. That rabbi didn't feel comfortable, so he reached out to another rabbi. That rabbi said, "Does she currently have ovarian cancer?" The answer was no. He said, "How can I justify this? She doesn't currently have cancer. How can we do this surgery? How can we remove her ovaries causing early onset menopause, causing her to be infertile if she doesn't currently have ovarian cancer?" So, he said no. Now I was personally a little surprised by that answer. So, we did some research and we shared some, we found out some of the studies about how accurate the screening is and how effective the surgery is at preventing ovarian cancer.

I approached a number of rabbis who are, let's say, understanding towards medicine and science, and I presented the question. All these rabbis I approached, and we published this after, said it is allowed by Jewish law. Why? But the response was, what about the fact that she doesn't currently have ovarian cancer? There's a category of Jewish law called the *Rodef*. *Rodef* is the concept that even though we're not supposed to kill someone by Jewish law, if someone is chasing you to kill you and the only way to save your life is by killing them, Jewish law allows killing the person. That's called the *Rodef*. The rabbi said, "The gene can be considered a *Rodef*." If we believe in genetics, we believe in the reality of our genes, so that is

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the reality. Even though she doesn't currently have ovarian cancer, she has the gene, we can take action now and a oophorectomy would be allowed by Jewish law to prevent ovarian cancer. And that was the methodology by which these rabbis allowed it, which I thought was just beautiful and very profound.

There's a lot more questions. I think I'm going to wrap up just because that's my time and I want to engage in the conversation. But lots of questions. The rabbis said, really, this testing should be happening by age 25 or so, but that's the whole discussion. Should we inform a spouse, a prospective marital partner, revealing confidential information? These are all issues that come up in Jewish law. A lot to talk about, but suffice is to say, the rabbis have really embraced the concept of genetic screening and really encourage it. This is really a basic part of healthcare, and Jewish law strongly encourages us to be involved in this great work that doctors Rybak and Cohen are engaged in. Thank you.

Jessica Jablon:

Thank you. That was very, very interesting. We're just so glad that you could be here to share that perspective with us because I'm sure that there were a lot of people who might not have thought that that is what the rabbis said and just very fascinating. So, thank you for sharing that. I wanted to get to some questions. There were a couple that were put into the chat. I'm going to start with the first one, which is regarding what you just were talking about, Rabbi Weiner, which is someone said, "I'm confused. I thought the fetus isn't a person until birth according to Jewish law."

Rabbi Dr. Jason Weiner:

Right. That's true. And that's a major reason why Judaism allows abortion when necessary because a fetus doesn't have status until it's born. The thing was, the rabbis in the Talmud when they discussed... The abortion discussion actually goes back to the Talmud. It's fascinating. Many of these discussions we're having to try to figure out how to apply ancient ideas to modern context. But abortion is discussed in the Talmud and basically the rabbis were concerned. They had concerns about it, but they basically said, if it's necessary to save life, of course. Saving life, by the way, includes mental health, emotional wellbeing in addition to physical health. So, the rabbi said it's allowed.

They limited it. There were some concerns. They mentioned some ways that they were concerned and they basically said, but it can be justified in so many cases. That's one of the discussions where they said a fetus in the mother's womb does have a status, even though it's not a status of a human. It has an intermediary status. That status can be overwritten, of course, for human needs but it has a certain status. It's like an intermediary status. But it has even less status if it's not in the womb, which gives us even more flexibility when it comes to genetic screening and things like PGD.

Jessica Jablon:

Thank you. Let me ask you. Sometimes there are different goals and values between patients and their medical staff. As a chaplain, how do you address those issues? Where do you fit into that process?

Rabbi Dr. Jason Weiner:

Our role as a chaplain is never to try to influence people or push them to do something that they... Our role is to try to help people uncover what's important and meaningful to them by simply asking good questions, being good listeners. Oftentimes, people need help expressing themselves and articulating what's important to them. Many questions that come up in the medical context... Thankfully we don't have to think about them. People aren't all as brave as all of you for coming out to a program like this and don't engage with great organizations like Sharsheret that create the conversations.

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Sometimes, they're forced to think about things for the first time that are very difficult questions. But if we can help people at least to try to navigate what's their narrative, who am I? What is meaningful to me, who's meaningful in my family? How am I making this decision? Who do I need to talk to? Am I truly understanding what I'm hearing? Sometimes as chaplains, we're just simply translating what the medical team is saying and helping to make sure that people are understanding what they're hearing. Because oftentimes, in moments of crisis, we don't really hear everything that's being told to us. We need someone to just help walk us through. So, a chaplain's role is not to dictate to people what they should or shouldn't do to or to be judgmental in any way, but to simply help people with their own decision-making process.

Jessica Jablon:

Thank you. Dr. Cohen, you mentioned that there's really no good screening for ovarian cancer. Is there anything down the pipeline? Is there anything coming that we can think about for the future?

Dr. Josh Cohen:

Thank you for that question. I wanted to bring up prevention and strategies, just not enough time in the presentation. Also, Rabbi Weiner, I just want to say, I've never heard a rabbi use the word blastocyst and I just want to acknowledge that. I'm so impressed. Congrats and just great work, wonderful medical knowledge and meshing of that, so thank you. There are things that we can do. For patients who do test positive, we do offer pelvic ultrasounds and CA-125 blood tests anywhere from every six months to once a year. Those are not great screening tests, but they do look at the ovaries. We can look at them with ultrasounds. The blood test is a protein in the blood called CA-125. That's a number that can go up and down for lots of reasons, especially for younger patients, including menstruation and fibroids. These are not specific to ovarian cancer, but outside of a specific screening test, they're the best that we can offer outside of risk reducing surgery, which is the salpingectomy or salpingo-oophorectomy.

I think things that I would recommend for patients, we know that the use of birth control pills does reduce the risk of ovarian cancer by 40%. If you're a younger patient and you're looking to regulate your periods or maybe have a form of contraception, if you take birth control pills for more than five years, you've automatically, whether you have BRCA or not, reduce your risk of ovarian cancer by 40%, which is quite huge when you think about it. That's a very simple intervention. Also, living a healthy lifestyle. There's no perfect diet, a Mediterranean diet. I think sometimes people ask about alkaline water and hemp. These are not things that have been well studied and are not going to be preventative for ovarian cancer. But I think for a certain enriched population of patients who we know have a genetic predisposition, we do offer screening with the form of ultrasound and CA-125.

It's not been shown to be beneficial at the moment, but really outside of having symptoms that you come into the office for, it's the best that we have. I would say the best that we can offer is certainly symptom management. If you're worried, please come in. And that's why genetic testing is important. I'm mean, my name's Joshua. That's why in our population of Ashkenazi Jews, it's just so important to do the testing if we can, to find those patients because it's a game changer for those families if we know. We are doing a study, I want to say it's a national study, City of Hope is part of it, where we believe most ovarian cancers are actually from the fallopian tube. High-grade serous ovarian cancer is the most common form of ovarian cancer. And we actually do believe we know where the precursor lesion is.

It's called a STIC lesion, serous tubal intraepithelial carcinoma, and it's within the fallopian tube. The fallopian tube hangs like a claw over the ovary. And over years, the fallopian tube cells slough off and end up on the ovary. And what we've been calling ovarian cancer for years in BRCA carriers is probably fallopian tube cancer. Now there's a movement for patients who are done childbearing or maybe or are BRCA positive, we actually are offering salpingectomy to

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those patients instead of oophorectomy. It's still a study, but we hope in the next 20 years to know what numbers of risk reduction we get for someone who does not want to remove the ovaries, but we'll remove the fallopian tubes, if we get the same risk reduction in a cancer for these patients. Answer's probably not the same full risk reduction, but it's going to be significant.

That may be an intermediate step for women who do not want to undergo oophorectomy but are wanting to do something. A salpingectomy doesn't change hormonal status. It does prevent you from getting pregnant spontaneously. That may be some data that can be helpful for people. It will be helpful down the road.

Jessica Jablon:

There was a question in the chat, Dr. Cohen. Do you discuss hysterectomy along with RRBSO, with BRCA1 carriers?

Dr. Josh Cohen:

Oh, yeah. That's a long discussion. The answer is there's more data coming out about serous carcinomas from the uterus. And I've evolved on this myself over the last five to 10 years, and there's really just a couple studies out. There may be an increased risk of serous uterine cancer for BRCA1 mutation carriers. The numbers are very small and it's really hard to say. The NCCN guidelines, which we all abide by, do not officially recommend a hysterectomy. I do now discuss it with patients who have BRCA1, the role of removing the uterus. I will tell you, where it does come into play for patients are if they are interested in hormone replacement therapy, which we do offer patients who are premenopausal. Removing the uterus does remove the need for progesterone.

We know that progesterone is the hormone that we need to keep the uterus safe from uterine cancer, but it's also the hormone that probably increases your risk of breast cancer. For women who want to have an estrogen patch or oral pills after they undergo removal of the ovaries, it can be a way to simplify the hormonal regimen. By removing the uterus, you no longer need the progesterone. You can be on either an estrogen patch or an estrogen pill. So, I do discuss it with my patients. Yes.

Jessica Jablon:

Christina, what is the best age to undergo genetic testing? What is the earliest, I guess, is really the question?

Christina Rybak:

Part of it depends if there's anything that's already been seen in the family. If there's no gene variant that's previously been seen, the main idea, I think, would be when we're considering starting cancer screening. Anyone who's interested in their level of risk could have a genetic counseling appointment. The earliest that we typically would even start screening for something like mammogram, if someone even were positive or breast MRI would be 25. If someone's already had a positive result in their family, then it would really be based on the specific gene variant that was found, if that makes sense.

Jessica Jablon:

Yeah.

Christina Rybak:

There are rare syndromes where there are childhood cancer risks, but that's uncommon.

Jessica Jablon:

Thank you. I like to see, there's some conversation in the chat with people sharing their stories, and I just want to acknowledge that we see that and thank you for sharing with us. Somebody

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has said that they had a hysterectomy, but they were not able to remove the fallopian tubes. I'm concerned if that increases my risk for further cancer. I think that's for you, Dr. Cohen.

Dr. Josh Cohen:

Yes. I'm not quite sure why they were unable to remove the fallopian tubes. There are rare circumstances if you had prior infection. My recommendation is find a surgeon at City of Hope, or maybe another comprehensive cancer center to give you a second opinion. But there are things that go into that, and if you don't have a BRCA mutation or other mutation that increases your risk of cancer, I can't say that you need to have the fallopian tubes removed. The American College of OBGYN, has now recommended removal of fallopian tubes for women who are undergoing hysterectomy in all settings, because we know it's on a population-based level. It is associated with fallopian tube and ovarian cancer. I'm happy to give you some more guidance. I probably need a little more information on your history to know exactly where to go with that, but just know that it's not a necessity that you need the fallopian tubes out, if you don't have a genetic predisposition as we've discussed today, but something that is recommended if someone's undergoing hysterectomy for other reasons.

Jessica Jablon:

There are a couple of questions that just came in. One is for the panel, how does one reach out now to get genetic screening? I guess, Christine, that's really for you. Who do they call? Phone number, website. And then again, I also do want to say that you can call Sharsheret and we can guide you with that as well through our genetic counselor. But Christina, please.

Christina Rybak:

Yeah, findageneticcounselor.org is the search engine of the National Society for Genetic Counselors. If you're looking to find someone, search near you or you can search for online resources. If you're interested in genetic counseling and testing, that would be where I'd refer you.

Jessica Jablon:

There's also a question in the chat that asks about support programs for Jewish women who need support due to genetic cancer. I would say that we are here for you, so please contact Sharsheret. Our social workers are amazing and they're here to guide you. If you're not talking about predisposition to breast, ovarian cancer, we can hopefully help guide you to places that can help you specifically with your needs. Last question as we start to wrap up for Rabbi Weiner, what are the biggest spiritual concerns you see in cancer patients?

Rabbi Dr. Jason Weiner:

There's a lot that I see. One that comes to mind immediately when... First of all, existential anxieties when people start thinking about the fragility of life and their legacy. These are oftentimes very big issues that arise. Oftentimes, we'll do things like try to write an ethical will or do things to actually think through one's legacy and talk through these things and have conversations with their families. One thing that I find with Jews oftentimes... I primarily work with Jews, so that's just my experience, but there's a lot of people, and truth is I see this a lot amongst Jewish women, that there is a sense of a need to care for others and want to take care of their family. Sometimes when one is the patient and one is sick and suffering, they're reluctant to accept care because they want to care for others.

Oftentimes, I'm trying to encourage people that it's okay to receive care from other people, and it's okay to share what you need and where your struggles are. You don't have to always put on a happy face and just pretend like everything's fine and that you're going to care for everyone else when you're the one who needs care. I think that that's an issue that comes up a lot. I try to encourage people to be open to simply receiving when they're struggling.

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Jessica Jablon:

That's so important. With that, Dr. Cohen or Christina or Rabbi Weiner, if there's anything that you'd like to add to wrap up for tonight, if there's one thing you want people to walk away with, what would that be?

Dr. Josh Cohen:

I would say know your family history, advocate for yourself, reach out. We're clearly dedicated to our wonderful Ashkenazi and Sephardic Jewish population here, but just know cancer impacts everybody. And that Sharsheret and organizations that are amazing like Sharsheret, all of us are here to help. But I think whether you have friends or family, anybody who's been impacted or there's a risk, it's okay to reach out and just know that no one lives in a vacuum. We're all here for you and thank you for being here tonight on this very important session. Thank you Sharsheret for helping to put this together. Great to Christina. Wonderful work with you. Rabbi Weiner, so wonderful. I learned so much listening to you talk tonight, so I just want to say thank you for participating as well.

Rabbi Dr. Jason Weiner:

Likewise.

Christina Rybak:

Thank you.

Rabbi Dr. Jason Weiner:

I will simply say that one thing we can see from the Jewish history is that as has been said so many times, knowledge is power. The more you know, the more you can do it. And talk to your rabbi. Judaism has so much support to provide in these situations, and thankfully the Jewish community has such great organizations such as Sharsheret.

Jessica Jablon:

Thank you. Christina, did you want to add a final thought?

Christina Rybak:

Yeah, just that was all amazing and great. I would just say genetic testing has become so easily accessible, so please do consider it and reach out.

Jessica Jablon:

Thank you. I want to just thank all of you, our incredible panelists for sharing this information. I learned so much. Every time I do one of these panels, I come away with so much knowledge. We're just so grateful for your sharing your expertise. Again, we want to thank City of Hope for sponsoring this series. And we want to thank Merck for their sponsorship of our programs. We've put an evaluation link into the chat. If you would take a minute just to fill it out, it really does inform our future programming.

We know how easy it can be to delay appointments, but if it's your mammogram checkup or genetic consultation, please make sure you're staying on top of your own health. If something doesn't look or feel right, don't put off calling your doctor. It really could save your life. Please know that our social workers and genetic counselor are here for you and your loved ones. Our number is 866-474-2774 and you can also email us at clinicalstaff@sharsheret.org. Please check out our website at sharsheret.org. We're on social media, on Facebook, on Instagram @sharsheretofficial. Please follow us. It really does make a difference.

Finally, we want to let you know about our next event in this Orange County series, which is the Journey of Healthy Living happening at the Merage JCC in person in Irvine on August 13th at 10:00 AM. Learn practical ways to reduce your cancer risk and live a healthier lifestyle from City

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of Hope, Orange County experts, including Dr. Cohen, who we heard from today. The link to register is in the chat. And save the date for the third event in the series, which will take place in person on October 30th at Congregation B'nai Israel in Tustin at 7:00 PM. More information will come soon on that.

We also offer Sharsheret virtual programs regularly, so please check out our website to see what topics are coming up. The link is in the chat along with a link to all of our past webinars. We've done hundreds of them over the last few years, and I encourage you to check those out. After watching tonight, you are all part of our Sharsheret, a link in our chain. So, please feel free to contact us with any questions and to share Sharsheret with anyone you might think would benefit from our support. Thank you for taking the time to listen and to be here today, and we hope to see you soon.

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 250,000 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

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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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