# Navigating Fertility: What Genetic Mutation Carriers and Cancer Patients Need to Know

National Webinar Transcript

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Presented by:

## 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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Melissa:

Thank you so much for being here. Thank you very much. Welcome. The focus of tonight's webinar*, Navigating Fertility: What Genetic Mutation Carriers and Cancer Patients Need to Know*, we'll explore something complicated, something that isn't spoken about as frequently as it should be and that is the intersection between carrying a hereditary cancer mutation or a diagnosis of cancer and family building. As always, before we begin tonight, I have a few housekeeping items that I need to share. There have been so many people involved with tonight's webinar.

I want to thank tonight's sponsors whose generous support enables Sharsheret to continue to provide high level educational and support programming. Thank you to the Basser Center for BRCA, Lilly, Merck, Novartis, and the Cooperative Agreement 240061 of the Centers for Disease Control and Prevention. I also want to shout out our amazing program partners for tonight's webinar. Their commitment to fertility and family building has helped to build many, many families. Thank you to Illume Fertility, I Was Supposed To Have A Baby, The Jewish Fertility Foundation, the Misconceptions Podcast, the Stardust Foundation, and Yesh Tikva.

As always, tonight's program is being recorded, but I want to reiterate that no faces or names will show on the recording other than those of the presenters. That being said, if you wish to turn your video off for privacy now, the option to do so is on the bottom left of your screen. You could also choose to rename yourself if you prefer to remain anonymous and you can do that by clicking the three dots on the top right of your photo square. Instructions are in the chat box now, including how to call in. We also have closed captioning. To display live captions on the bottom bar, click captions and then simply show captions. Everyone who registered for tonight's webinar will be notified when the recording and transcript of today's program is posted on the Sharsheret website. Please feel free to share that link with anyone who may be interested.

We received some great questions through the registration process, but as questions arise during tonight's presentation, please use the chat box and we will address them during the Q&A session at the end of the webinar. As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for 25 years because cancer is so much more than simply a physical experience. As we move into the webinar itself, I want to remind you that Sharsheret is a not-for-profit cancer support and education organization and does not

provide any medical advice. The information provided this evening by Sharsheret and by the presenters is not a substitute for medical advice or treatment for a specific medical condition. As always, seek the advice of a qualified healthcare provider with any questions you may have regarding your situation.

Before we ask tonight's experts to join us on the screen, we will welcome two experts of a different type, those who have been through or are going through this now. As you listen, you'll hear two very different stories. First, we'll hear from Ashley and then Chloe will share her story. Ashley, welcome.

Ashley:

Hi. Can you guys hear me okay?

Melissa:

Perfectly.

Ashley:

Great. My name's Ashley. I'm going to tell my story. When I was 34 years old, I froze my eggs. My OBGYN encouraged me to think that as a fertility insurance, more like a backup plan. She was careful to remind me that it wasn't a guarantee, but it could give me options in the future. At that time, I thought I was simply taking a precaution for the future I couldn't predict. I had no idea how important that fertility insurance plan would become. Over the next few years, life unfolded in ways I never anticipated. We experienced three miscarriages and I was diagnosed with Graves. Eventually, we decided to pursue IVF and create embryos using the eggs I'd frozen years earlier. During my third attempt to prepare my uterine lining for an embryo transfer, I noticed changes in my breasts. Deep down, I knew it was cancer, though I spent time trying to convince myself otherwise.

At 38 years old, I was diagnosed with estrogen and progesterone positive HER2 negative invasive ductal carcinoma of the left breast. Despite being of Ashkenazi Jewish descent, I have no genetic predisposition or family history of breast cancer. After my diagnosis, everything changed overnight. After meeting with my oncology team and developing a treatment plan, I received a call from an incredible oncofertility nurse. She explained my fertility preservation options before cancer treatment began. By that point, I had already began. I had already been through so much. I was exhausted physically, emotionally, and financially. I felt like I had nothing left to give. But after conversations with my nurse, my partner, and my supportive coworkers, I decided to undergo one final egg retrieval before starting treatment. Unfortunately, it was unsuccessful. Oddly enough, I found peace in that outcome. Although there were additional retrievals I could have pursued, I chose to stop. I had done everything I wanted to do.

With that decision made, I turned my full attention to treatment. After surgery, my treatment plan included chemotherapy and endocrine therapy. My oncologist continues to remind me of studies showing the temporarily interrupting endocrine therapy after 18 to 24 months to pursue pregnancy is safe, although I never planned to pursue that route. Before cancer, I likely would have continued trying to become pregnant myself. After cancer, I no longer want that path. The losses, the treatments, the uncertainty, and the reality of everything my body has endured

changed something inside me. Cancer forced me to let go of the future I had imagined and considered a different one, that was an incredibly difficult decision. Then after years of challenges, disappointments, and setbacks, the stars finally aligned. We matched with the most amazing surrogate, Rachel. Today, she's 26 weeks pregnant with our baby.

Sorry. There are still moments when I can't believe I'm standing here telling the story and while this chapter is filled with joy, I haven't forgotten about the hardships that come before it. This journey has taught me that fertility is not a guarantee. Health is not a guarantee and life rarely unfolds according to our careful constructed plans. But it also taught me something about resilience, about accepting help and about advocating for myself and about finding hope even when the path looks nothing like the one I had imagined. Most importantly, it's taught me that there is more than one way to build a family. My story includes infertility, miscarriage, IVF, cancer, surgery, menopause, and surrogacy. It's not the story I would've written for myself, but today as I wait to welcome our child into the world, I can finally say that it's a story filled with hope.

Melissa:

Thank you so much Ashley for sharing your story.

Ashley:

Of course.

Melissa:

We are going to welcome Chloe to the screen to share a very different story.

Chloe:

Oh, that's very tough to follow. Thank you, Ashley. What a beautiful story. Myself, a bit about my background, I got married about four years ago and a year prior to getting married, my husband's mother spoke to her doctor about her family history and the doctor suggested that she be tested for BRCA. She was surprised to find out that she was BRCA positive and as a result, her children then were tested. My husband unfortunately tested positive for BRCA. At the time, we really didn't think about what this diagnosis meant for us and our future. And after we were married, we unfortunately had several friends who experienced cancer. A very dear friend of our sister passed away at the age of 25 and we took the time of inflection to think, "What can we do to help build a safer future for our children?" And so we reached out to Sharsheret.

Sharsheret was an incredible organization to help navigate this scary journey, something that I never imagined. I thought I would have that trying phase and the excitement of telling my family and all of the surprises that would come from it, but I had different surprises and I tried to embrace that journey. And so learning about all of the different paths was something that I really enjoyed understanding what I would be able to do. And we did the IVF journey. It was really hard. I didn't recognize how many of our embryos would become BRCA positive. Out of so many eggs that I was able to retrieve, I only received one embryo after all of that, but thank God that was my daughter that I have today. And sometimes all it really takes is that one. And I'm so thankful for her and the journey that I was able to have.

And now I'm also expecting my second same fertility journey. And it really is just a testament to science and believing in the process and understanding the trials and tribulations, but to achieve an outcome where hopefully future generations do not have to experience those same painful issues.

Melissa:

Thank you so much for... Thank you. You know what? Thank you to both of you for sharing your truly incredible journeys with us. As tonight is intended to be a unique, supportive and safe space for everyone, we'd like to take a moment to acknowledge that every person's experience and path is different. The stories shared tonight are honest, raw, deeply meaningful, and there is so much we can learn and take away from them. At the same time, we recognize that these are just two experiences among the many different journeys represented on this Zoom. For some, these stories may feel deeply relatable. For others, they may reflect experiences that are very different from our own. No matter where you are in your journey, there is something powerful in hearing from other women who have walked their unique and yet in some ways similar paths. We hope it reminds you that you are not alone and can offer moments of connection, hope, encouragement, and insight as you navigate your own experiences.

I also want to remind you that after tonight's Q&A session, we're going to be hosting two brief breakout rooms moderated by Sharsheret clinical team members. There will be one for those who are affected by hereditary cancer mutations and another for those who have or have had a cancer diagnosis. This will be an opportunity to ask questions, share your thoughts, be in the company of those who understand your experience.

Okay. Now I want to welcome this evening's presenters. We are so very fortunate to have both of them with us tonight. Dr. Ilana Ressler of Illume Fertility is double board certified in obstetrics and gynecology and reproductive endocrinology and infertility. She earned her medical degree at Case Western Reserve University and completed her residency at the University of Illinois at Chicago and completed a fellowship in reproductive endocrinology and infertility at the University of Cincinnati. She's consistently named a top doctor by Castle Connolly and is also a former member of the editorial board of Fertility and Sterility, the American Society for Reproductive Medicine's Premier International Journal for those who treat infertility and reproductive medicine. She's also been an expert reviewer of the latest gynecological surgical studies and has written literature reviews for the Society for Reproductive Surgeons.

Also with us tonight is Dvora Entin, LCSW, CST and PMHC. Dvora is a clinician specializing in reproductive and perinatal mental health and sex therapy with advanced training through Postpartum Support International, ASRM and the MISS Foundation and Bereavement Care. She serves as a clinical consultant to multiple nonprofit organizations and is the lead trainer for Postpartum Support International teaching about perinatal loss and postpartum health. She's also an adjunct professor at the Wurzweiler School of Social Work and developed maternal mental health coursework for MSW students and teaches clinical case intensives. Dvora maintains a group private practice in Philadelphia and presents nationally on reproductive mental health and clinical support for individuals experiencing maternal mental health challenges. She also hosts a podcast called Misconceptions that's available on all major platforms. First, we'll hear the medical, the physical considerations followed by the psychosocial

and emotional impacts. Then we'll have time for the Q&A, so please enter any questions you have into the chat box.

So Dr. Ressler, you are up first. I know we have to give you a second to share your slides.

Ilana Ressler:

Hi, thank you so much. Let me just share my slides here with everyone. Okay, perfect. Hopefully you can see and hear everything okay at this point. Thank you so much for the warm welcome and I'm really excited to be here discussing this topic with everyone. Tonight is a huge topic, so I'm going to do my best to stay within the time limit and cover the pertinent parts, but of course meeting individually with a reproductive endocrinologist to discuss one's own journey is an important step for anyone who has these considerations. So first we're going to really focus on mutation carriers and what really should be considered in regards to fertility. So first and foremost, we should just state that most cancers are not hereditary. Most are spontaneous. They can be due to various different reasons, environmental and other things, but about 5 to 10% are hereditary, meaning there is a specific mutation that is passed from one generation to the next.

The most commonly known ones are BRCA1 and BRCA2, which for the general population, affects about one in 400 to one in 800 people. But of course in Ashkenazi Jews can be basically one in 40. So if there is any question about whether someone should be tested, there are official criteria from the National Comprehensive Cancer Network that goes through risk factors and delineates who might be a good candidate for being screened. My practice, for example, reproductive endocrinology and infertility, we're a general fertility practice, but we do have two genetic counselors within our practice and we do offer this sort of testing for our patients if interested. In terms of what really should be considered if someone is known to be a mutation carrier, really two main thoughts. One is to consider fertility preservation proactively and the other is the ability to screen embryos and avoid passing along that mutation to children. So why should someone consider being more proactive in terms of fertility preservation?

Well, a couple of reasons. One, just by virtue of being a carrier, for example, of BRCA, there are studies showing that carriers of this mutation actually have lower ovarian reserve or quantity of eggs. So compared to others who are non-carriers, markers of ovarian reserve or quantity of eggs, there are three main markers that reflect this. Two are hormones, anti-Müllerian hormone, AMH, day three FSH and follicle count. These have been shown to be lower, meaning that the reproductive window might be just shorter in general for those who are carriers. Also, obviously when being a carrier, there is an increased risk of cancer and this could really accelerate the process in terms of thinking about family building and preserving for future, which we're going to get into a little bit more in the latter part of this discussion, but it is good to be thinking ahead and preserving for future and also to test, again, embryos, which we're going to talk a little bit more about.

So first, just generally about ovarian reserve. As you may or may not know, we were born with all the eggs we're ever going to have. So, we had about six or seven million before we were born. By the time we're born, about one or two million, puberty, half a million and they're just rapidly lost throughout our life until menopause, that's when they're gone. So, the average age of menopause in the US is 51, but starting in our mid 30s, slowly there starts to be a change in terms of both egg quantity and egg quality. So that total number is going down and then the number of healthy ones is getting fewer. And this is just for everyone. So, in general, all women I think should think about their future family building goals and freezing eggs. And the lifespan has continued to get longer and longer, but the age of menopause really hasn't changed and it's really somewhat of an accelerated track.

So, the ways that we have to preserve fertility are by egg freezing, also referred to as oocyte cryopreservation, embryo freezing and of course for men, sperm freezing. These are ways to help increase future success. Unfortunately, there's no guarantee. There's no guarantee that if by freezing eggs or embryos, they will one day become a live birth, but it certainly will increase the likelihood of that happening if not done. And the future success of the use of those eggs or embryos is directly related to the age at which they were frozen. So, the optimal time is before the age of 35. Not to say it can't be done after. Certainly a 36 or 37-year-old egg is going to have a much higher chance of success than a 42 or 43-year-old egg, but really the younger the egg, the better in a sense. This just demonstrates... There's a tool online. If you Google egg freezing calculator, you can plug in the age at which someone freezes the eggs and how many. So, generally speaking, for women under 35, it's recommended to freeze 12 to 15 eggs for any one future live birth.

So, you can see at the age of 35, by freezing 12, it's about a 75% chance of having one live birth, 39% of having two, 14% of having three. This goes down. So, at 37, you can see the chance of having one goes down to 56 and by the age of 40 to 35. And this really is speaking to the quality. It's the same quantity, but quality is going to be declining as well. So how do we freeze eggs or embryos? I'm just going to walk you through briefly how this process is done from a medical perspective. So, I always start by going over what happens in a natural cycle. Every one of my patients sees this diagram very often because everything we do is a springboard from what's happening naturally. So, every month we have a bunch of eggs, a group of eggs waiting ready for use.

These are contained within little structures called follicles, which are visible on ultrasound in the ovaries. Eggs are not, but we can see the follicles. And naturally, our brain makes this hormone FSH. One follicle will grow bigger than the rest. That's the dominant follicle, which is making estrogen, which is then developing the lining of the uterus. Mid-cycle, the LH surge triggers the ovulation and that side in the ovary becomes the corpus luteum and makes progesterone. If no pregnancy occurs two weeks later, the estrogen and progesterone levels fall and a new cycle begins again. So, all of our treatments are a manipulation of what is happening. So, I think it's important for everyone to understand the basics of this cycle for creating... Or controlled ovarian hyperstimulation, which is the medical term of stimulating the ovaries to get many follicles to grow, which this process, by the way, for freezing eggs or embryos is the same up until the point the eggs come out.

If they're frozen alone, that is egg freezing. If they are combined with the sperm right away, that is in vitro fertilization and then the embryo would be frozen. So, the medications that we use to stimulate the ovaries are these same exact hormones. These are just examples of FSH. This one has a little bit of LH and this is a medication that helps prevent ovulation because we don't want someone to ovulate and release the eggs before they come out. These are given by subcutaneous injections on average for about 10 days before the eggs are ready to come out and we're monitoring closely through ultrasound and blood work. So, this is an ultrasound image of an ovary before it's stimulated. We see nice number of little follicles here waiting for use. And then with the stimulation, the follicles grow, we measure the diameter and once they get to a certain size, the egg inside should be mature and capable of fertilizing. And so, we set someone up for the retrieval.

The retrieval is done in a surgical suite. Every center does it a little bit differently, but patients do get IV sedation. They are asleep and comfortable. They do not feel anything when undergoing this procedure. And essentially an ultrasound is placed once a patient is asleep. It has a guide along it for the needle. The needle is passed through the vaginal wall into the ovaries, specifically into the follicle, which contains an egg. You can see it's drawn in this illustration. Of course, in real life, we cannot see the eggs, they're microscopic, but we drain the fluid and along with the fluid should come the eggs. You can see the ovary is located right on the other side of the vaginal wall. So, it's really a short distance that we have to access the ovary and we train all the follicles.

And then once that's completed, we do the same thing on the opposite side. So essentially, it's a couple of needle sticks. There's no big incision or suturing. It's a very minimally invasive procedure. I think it's somewhat like a blood draw, but obviously we're going into access a different part of the body. I just wanted to show you, this is a photo from our retrieval room. So patient would be here. Here's the ultrasound. This is what we see. We see the ovary, we see the needle, we guide it into the follicle, and then we drain the fluid into the test tube. Behind this wall is the IVF lab and this window is open during the procedure. As the tube fills, our assistant hands it off. It's given to the embryologist who looks under the microscope, finds the eggs, separates them into another dish and counts. So, before a patient leaves that morning, the total number of eggs would be known and relayed to the patient.

So, this is what eggs look like under the microscope. This is what sperm looks like. If freezing eggs, again, these would be frozen and for future use. So, this maintains the autonomy of the future reproductive choice. Then any sperm of one's choosing would be used for later creation of the embryo. If someone has a partner and knows that's who they want to have their children with, we would right away take the sperm, combine it with the egg to create the embryos, and then they develop to a certain stage called the blastocyst. So as mentioned earlier, there is a high rate of attrition as going through this process. A certain number will fertilize, a certain number will make it to blastocyst and then at that stage, they're frozen. Now here comes the part that's relevant for the hereditary cancer carriers is that we can test these embryos then to see if they have the marker, if they have the mutation.

So, before the embryo is frozen, a little biopsy is taken from the outer part of the embryo, the trophectoderm, and the embryo is frozen. And then that biopsy sample is sent to a genetic testing company to screen whether that mutation is present or not. So, this is referred to as pre-implantation genetic testing for monogenic disorders or PGTM. Along with PGTM, most commonly PGTA is utilized, which is a much more common technology because this is screening for the number of chromosomes. Does it have the proper number or two sets of each number of chromosomes to make it chromosomally healthy? Because really at the end of the day, it doesn't matter if it's a carrier of BRCA or not. If it has an extra copy of chromosome 18 and missing a copy of chromosome 20, it wouldn't result in a healthy child. So, these are paired and go together.

And the numbers dwindle very quickly in terms of PGTA testing, this is an idea of how many we would expect to be normal versus abnormal. So, this is percent of embryos that are aneuploid, which are chromosomally abnormal. This is the age at the time the eggs come out. So up until the age of 35, about 30% of all embryos will be abnormal, but this really exponentially increases

afterwards. So, by the time someone is 40, 60% will be abnormal. By the time someone's 42, 75% and upwards. So, at a certain point by our mid to upper 40s, no more eggs will be healthy. So again, the optimal time to do this is when someone is down here on the curve. And then in terms of how many will be a carrier for a mutation or not, most of the time it's 50/50 chance. So that can eliminate then half of those that are chromosomally healthy.

So, it can often take many rounds of doing the treatment if someone has the time to do this and is able to, it can take several different attempts. Now just to shift for a moment to other considerations, let's say someone is a BRCA carrier, they're probably going to be advised to have their ovaries removed at a certain age. Obviously, that will eliminate their ability to conceive unless they've, again, frozen eggs or embryos previously or sometimes fallopian tubes are removed to reduce risk and that would eliminate the ability for the eggs and the sperm to meet in a natural manner. So again, IVF can be done to transfer an embryo into the uterus. So briefly, I just want to, for a couple more minutes, touch on the fertility preservations with those who do have a cancer diagnosis. Really, this is when it's more or less a fire drill.

So, someone is given a diagnosis of cancer. Of course, the priority is to think about treating the cancer, what comes next, surgery, chemotherapy, radiation. So, a lot of these treatments in particular, chemotherapy, and if it's radiation to the pelvis, can be gonadotoxic, meaning toxic to eggs and affect future fertility. So, while there is an urgency to treat the cancer, it's also important to try to think about, even though it's a time very difficult to think about these things, but future family building because the window can be closing. So, this is just a list of all the different methods of fertility preservation. I'm not going to go through each one, but I just want to highlight the gold standard is what I've just reviewed with you, egg and embryo cryopreservation. So, if someone is able to undergo that treatment, that is really going to be the priority.

Others include freezing ovarian tissue. This in particular can be done for children or pre-pubertal females and other methods. The ones in italics are really still considered experimental, so they shouldn't be considered unless the others are not feasible. And then for men, of course, sperm freezing, sometimes that can be surgically removed, if need be. So, the window of time in which this is often done, let's say someone is diagnosed with breast cancer, they're planning to have a surgery, that would often be done first. Then there's a window of time usually in which they are healing from their surgery and going to be starting chemotherapy. This is kind of our window to jump in. It takes about two weeks to do this process of egg or embryo freezing. If someone has additional time, perhaps they can do more than one cycle. And then there are alternative methods.

Not everyone is able to freeze eggs or embryos. Someone can use someone else's egg. This is called donor egg or donor sperm or even donor embryos. As we heard earlier, certain situations may involve use of another person to carry a pregnancy, a gestational carrier. And of course, adoption is an option for family building as well. So many different ways to create a family. And really all of this takes a team. So of course there are the oncologists, medical, surgical oncologists, reproductive endocrinologists, genetics counselors are involved and mental health professionals are a very important piece of this. So, with that, I'm going to segue into the next part of our talk with Dvora. I'm going to stop the sharing here because she's really going to pick up and talk about the mental health aspects of this process as well.

Dvora Entin:

I'm impressed how you just did that in 15 minutes or less. That was really impressive. So, thank you. Thank you so much for setting the stage. And I will say to you, it's so interesting because hearing the physician's perspective and then knowing the patient's perspective and knowing the psychiatric or psychological perspective very often are very different experiences. And I had to giggle. I did giggle. I did laugh when you said, "It's kind of like a blood test." I'm like, "Except that your feet are in stirrups, you're sedated and someone's sticking a probe up your vagina. But other than that, it's just like a blood test." So, I think we need to be... You'll hear me a little bit of humor in this space, but we do want to confront that there is an extraordinary amount of emotional potentially distress, potentially emotional power that goes into every single slide that was presented a moment ago. Every single line of that slide holds emotional intensity.

And so we want to set that tone of, yes, we are at a state of medical miracles, frankly, where these options were not available 10, 20, 50 years ago. And there's so much here that's available medically and scientifically. And sometimes I actually think that the psychiatric or psychological implications of those choices haven't caught up. Our studies are not there. We don't have fabulous data about the psychological implications of all of these choices. That doesn't mean we don't want them. It just means that we want to tread carefully into this space with the sensitivity and understanding that yes, it's there, it's available, it's amazing. And we have trained physicians to do it and it's an incredibly heavy and humbling experience to walk into those doors. And so, I want to just think about it from the first thing that struck me, the first moment, when I think about these things is partnered or not partnered.

So, when we're talking about somebody who is a carrier, whether you're partnered or non-partnered or unpartnered or not yet partnered, that very often will set the conversation of, how am I taking this information and what am I going to do with it? But even just walking into an office, walking into a fertility office highlights the aloneness for those that are non-partnered. The fertility preservation of a younger person who is like, "I'm not yet married and therefore I'm going to save my eggs at the age of 30 versus preserving them or waiting for somebody to come along at 35." That unpartnered space is incredibly lonely in a fertility experience. When they are partnered, so yes, they may have somebody to walk in the door with them, but there's also, I think, a lot of "How did we end up here?" So, on one hand, it's an empowered space of, "I have this knowledge about my genetics. I'm aware, I'm knowledgeable, educated, and now I'm showing up in a fertility space that I actually probably could conceive on my own if I tried."

And yet there's a threat of solo conception or of unmitigated or unmediated conception. Is that even a good word? I don't even know. But okay. But you get the point. The idea of like, I have no... Maybe I can even conceive naturally, but that's risky if I want to protect my offspring from carrying a genetic disease or the potential of a cancer diagnosis. So, I'm not actually infertile. I don't actually have a fertility diagnosis, but because of my genes, I do. And so, the disruption of that space, the disorientation of walking into that office, going like, "What am I doing here?" can be very, very startling to those that are about to walk in that door. Or once you walk in the door, that really, I think, hits you in the greatest way.

In addition to that is a feeling of just the general of, how did I end up here? That question of like, "Wow, this is big girl stuff." And so on one hand, we're empowered. Other hand, we're like, "Oh my gosh, I'm not ready to be an adult just yet, even though I'm 34, 35, 37. I don't want to do this.

I just wanted to have a relationship with my loving husband and have romantic intercourse and have the beautiful conception and excitement."

You heard that in one of our presenters, like, "I didn't get to have the, ooh, I'm so excited moment." And all of that is taken away. And so yes, on one hand, empowered, thankful that I have options. On the other hand, there is a deep grief related to, this is my story and this is a story that I have to learn how to live within that dialectic, the dialectic of, I'm so grateful that I have this option and I'm also so sad that this is the option I have to choose. And there's another piece of this that I think is important to acknowledge that not everybody chooses that option, meaning they may say, "Actually, I'm not going to go through IVF. I don't want to walk in that IVF. I don't want to walk into Illume. I don't want to meet Dr. Ressler. I don't want this to be part of my identified story. I'll meet you in Shul, in the synagogue, but I don't want to meet you at the office. I don't want this to be part of my story."

And is there maybe possibly, because we're really good at guilt in the Jewish world, is there guilt that goes along with that? Am I burdening my child? What does it mean for my family's story? Will my child be upset, resent me, angry at me for creating them with the potential maybe of being a carrier to BRCA, to a mutation and to a BRCA mutation? And so, I think that that's something where we have to acknowledge and maybe admit that not everyone is going to choose the IVF journey, especially because IVF is expensive.

And for many states, this is not going to be covered. And for many organizations, they will not cover this because it's not exactly seen as fertility preservation. And so, I just want to acknowledge that the choice to walk in the door is equally as complicated as much as it is to not walk in the door. So, it's not a matter of I'm going to close my eyes and pretend it doesn't exist. It's I'm very aware of what it is. It's I'm still making the choice not to go down that road. So we want to always not assume that everyone's going to choose that. It's an ongoing discussion and an ongoing conversation. The other piece I think that just to think about of sitting in that room with people while you're a carrier but not yet diagnosed is you're not sick. And so for some people sitting in that infertility space, looking at all these people that have a diagnosis probably of infertility, it's a feeling of like, I don't know that I belong here.

I don't know that these might not be my people. I don't have this like, I've been trying for three years and we didn't get pregnant and we're taking sperm samples. I don't have that as part of my story. And so again, that disorientation can really sit on a heart and sit on an emotional experience. I'm going to talk in a moment about when there is a known cancer diagnosis, but just from an emotional perspective, I want us to begin by acknowledging that this is hard. Even from an empowered space, this is hard. Even from an educated space, this is hard. This is an experience where it's not what I thought it was going to be like. Even if I've known my whole life that I had the diagnosis or I have the genetic mutation. This is not what I thought it would be like. This is not how I thought I would create my family.

And so, the acknowledgement of the emotional intensity of that and potentially the emotional distress. We know that we've done studies of women who are going through infertility treatment and the rates of anxiety are something of like 40% at clinical levels of anxiety. And those are just those who disclose and that's only the person who's sitting in the chair, meaning the patient

in the bed and not even talking about their partner or spouse. So, we know that the entire process when there is a, we've been trying to conceive and have been unable to conceive, results in a very high level of emotional distress. So we know that these are individuals who struggle with anxiety, who struggle with depression, who struggle with hopelessness. We know that this fertility experiences, IVF process where procedures often result in feelings of potentially are traumatic, potentially are things that are very difficult and triggering, especially for those who have a history of child sexual abuse.

If you're an assault survivor, these spaces, feet and stirrups, very, very vulnerable spaces. So, we know that they're at greater risk of things like PTSD. And then we have to acknowledge that it can wear at the fiber of the relationship. Maybe one is on board, and one is not as onboard. Maybe one wants to do this and the other is not so keen to do this. So that kind of tearing at the fiber of a relationship is also something that needs attention. And so many of our clinics nowadays are very much ... I love that you're integrated, of course, with a genetic counselor. Many of our clinics are also integrated with the behavioral health, with mental health support and with social work to try to make sure that we really are looking at the whole process and the whole experience because it does impact relationships and self-identity and our relationship with our body and what we want our body to do and what our body might not be doing and what we wish it was doing better.

And thinking about just for a minute or so before we move on to questions and thinking about the realities of a known cancer diagnosis, where the reality most likely is going to be that you're going to have to use some kind of alternate family building capacity, as you mentioned, the donor experience, donor or using a gestational carrier. First and foremost, I think it's important to acknowledge that this is absolutely being done in the Jewish community and it is as well being done in the religious Jewish community and the Orthodox Jewish community as well. So sometimes I've heard people online who will say things like, "Oh, the Orthodox don't do that." Actually, we do and actually it's being done more frequently that you may be aware of. So first and foremost, that there is so much available and there's so much pain in having to choose this as your option.

And so again, that dialectic of, "I'm so grateful I'm alive. I survived cancer. I'm so sad I will not be able to carry my own child. I will not be able to feel that baby move in my belly. I'm so sad that some other woman gets that experience for me." And so I think this is where we sit in this process, this carrying of both. It's the carrying of gratitude and sadness, the gratefulness as well as the grief. This is where we are sitting in that psychological space. And again, if you have a history of mental health concerns, if you have a history of a diagnosis of anxiety, depression, that's a risk factor. And so it's something that I always would encourage you to bring up in pursuing any of these options that has to be part of the conversation. It's not just the body is connected to the head.

Our insurance company doesn't always agree with that, but our brain is connected to our body. And so, I want to remind you that we want to, as much as we're acknowledging the physical needs of our body, the emotional needs of our body are critical to pay attention to. It is our responsibility to make sure that we remain intact and healthy and whole as we prepare for whatever comes next in our family planning and family building experience. So, with that, I will turn it back over. I think it is to Melissa. We'll take some questions and we'll build off of that.

Melissa:

Absolutely. And we're all up now and I commend both of you for being able to do so much in such little time. We do have time for a few questions. So, I think we're going to shoot for going back and forth from emotional and medical, but can you explain, Dr. Ressler, the guidelines for stopping and starting endocrine therapy post cancer treatment so that someone might try and conceive? Because a couple of people asked that question.

Ilana Ressler:

Sure. So that really is a decision made with a patient and their oncologist that when is the appropriate time that someone might be able to put a pause in their treatment and because one can't be on endocrine treatment and conceive at the same time, it has to be stopped. So that's really, we look for the oncology team to work with an individual patient to really make that decision. We are mindful that we want to be expeditious during that window of time. So, while one might try naturally reproduction, I say this over and over every day, reproduction is very inefficient. It takes many months of trying, often under natural circumstances. So, we have to really think about expediting that while being off of that treatment and perhaps that means someone's already frozen embryos, certainly that's the quickest, right? You prepare for an embryo transfer and you do the transfer and that offers the highest chance of success, but maybe someone hasn't previously done IVF.

Maybe someone wants to try through other methods like ovulation induction. So, there are different paths to pursue and then once finished with the pregnancy after delivery, then again, that would be planning with the oncologist in terms of when to restart that treatment if recommended.

Melissa:

Thank you. That's helpful. Dvora, you talked about the strain for those who are partnered that any of these decisions might place on the relationships. So, someone asked, "What are some things I can do to protect my relationship from exposure to this level of stress?" You are muted.

Dvora Entin:

I think the main thing I want us to remember is that the relationship, and in this case, I'm going to call it a marriage, the marriage needs to come first. So, if I build a house but the foundation is totally rotted out, my house is going to collapse. So, building of the house being my family building, but if I haven't nurtured the foundation of this relationship, then I'm going to be so excited to get to the place of, I now have a family and my husband's like, "Wait, where did you go?" I left him back there. And that often is what happened. I remember having a conversation with somebody about this and the client said to me, she said, "I'll focus on that when I'm done." And guess what? She gave birth and he was sleeping on the couch. We must always nurture that relationship while we're going through it.

Nurturing a relationship means spending time together. Nurturing a relationship means talking to each other about things that are non-fertility, non-cancer, not scary, non-crisis, right? Talking about a funny... Going to see something funny, watching a clip, watching a movie together, just talking to each other about something other than what you are going through medically and remembering that sometimes your spouse can be the person who can receive the intensity of what you're holding, but sometimes your spouse can't be the only one. And that's why it's critical

to reach out to get support groups. I know that we're talking to an organization that thrives and supports so many. So many people thrives on support groups. This is what we do best, right? Making sure that you reach out and get support so that your spouse is not the only person that you have available to hold you in this intensity.

So nurture the marriage, just like you would any new relationship or any existing relationship, but just don't forget about it because you're so busy with something else.

Melissa:

Thank you. That's helpful. Here's something that we didn't talk about that I think might be on the mind of a lot of people. So do fertility treatments increase or possibly even reduce cancer risk? I guess the question is, do they impact cancer risk for someone who carries a genetic mutation, hereditary cancer mutation, or someone who has a personal history of cancer?

Ilana Ressler:

Yeah. It's a great question. So fertility treatments are not known to cause cancer. There are certain considerations that we take when doing treatments for those who, in particular have, for example, estrogen receptor positive or progesterone receptor positive cancers because these treatments are super physiologic. We are really increasing levels much higher than what they are naturally. It's also for a very transient amount of time. So it's for one cycle from start to finish, from the time a period starts to the time the next period. It's still about 28 days when doing this treatment. It's really only within a small duration of time within those 28 days that these levels are really elevated. But we do have considerations, for example, use of a medication that will keep estrogen levels lower. They won't impact the outcome. They won't decrease the number of eggs retrieved or number of embryos created, but they will keep overall estrogen levels lower during the treatment and other measures to take such as that. So no, they do not cause cancer, but we do take that under consideration and alter our protocols.

Melissa:

Thank you. Someone just asked in the chat a question that goes very well with a question that was asked earlier. Someone said, "What about someone who has a high risk diagnosis, cancer diagnosis and has to start chemo sooner than later?" And then somebody asked earlier, if someone has chemo or radiation or whatever, without being able to do fertility preservation, do you find that there's still a possibility for a healthy pregnancy and childbirth or do these drugs just completely damage a person's ability to conceive hopefully?

Ilana Ressler:

Yeah. So I think the first part of the question, if someone needs to start chemo right away, can we still do the fertility preservation? Generally, there's still like a two-week window. It's not necessarily the next day that someone is starting. There's planning that goes into chemotherapy. When we're planning IVF for someone who is not under these circumstances, there's a certain time in this cycle. We want to start at the beginning with a period or we put someone on a birth control. There are different ways of transitioning. That goes out the window when we need to do this in a cancer situation. Wherever someone is in her cycle, we can start right away and that really doesn't affect outcomes in a negative way either. We can start...

We can make it happen really within the next day or two that we can start someone. We have a whole team designated, most clinics do. For patients in this situation, we can get medications right away, arrange for the appointments and really ... So I think there are very few cases in

which there's really no time at all. Of course, there are other considerations as well. Now after chemotherapy, yes, there can still be eggs remaining. It can though lower ovarian reserve. There can be damage like DNA damage that is done, but it doesn't eliminate the chance of having children in the future. So certainly, we have patients who are cancer survivors and didn't preserve fertility and are ready to build their families at that point and they can be successful as well.

Dvora Entin:

Can I just also acknowledge just one thing on that?

Ilana Ressler:

Please.

Dvora Entin:

Dr. Ressler, you bring up the idea of like, we're going to do this, we're going to do this quickly. I just want, again, from the psychological, that movement from, I just got a cancer diagnosis to, oh my God, I'm getting shot up with drugs. And yes, we are amazing women to be able to be like, "We're going to just do this because this is important to me and this is what I'm being counseled to do." And I think what we see is there's often an aftershock, like the aftershock comes several weeks or even months later where you followed the rules, you follow the directions, you've got the shots, you've got the retrievals, you got everything done and you are then kind of like... You're a few weeks into treatment, months into treatment or even finished treatment.

And then there's this moment of, what just happened to me? And I did everything I was supposed to do. I did everything right and I'm so proud of myself. And also, I can't sleep at night or I'm also having flashbacks or I'm actually having nightmares and that there may be some risk for PTSD in these spaces. So, I want to be mindful of this idea that we check all the boxes physically and that's absolutely the jobs of the physicians and also to recognize that there's this entire other emotional component that's happening at the same time, this other narrative that's going on at the exact same time. And I know that our docs are paying attention to that. I want everybody else who's listening to remind you that in the future, everything's good now. We're healthy now. We even have several frozen eggs or embryos and you can still feel the aftershocks of that intense experience.

I just would love for you to clarify one thing. One of the things we know about for fertility preservation is if we usually are doing several rounds so we can get a certain number of eggs or embryos and that might not be available for somebody who's in that tight window of most recent and urgent cancer diagnosis. Do you want to just speak to that a little bit about that we're not going to get to be able to do ... Usually we're not doing three to four months of fertility preservation.

Ilana Ressler:

Correct, correct. So, it takes again about two weeks for that actual process of the injections. Again, about 10 days or so, two days later is the retrieval and then it's another two weeks until the next period begins. And even that is another stimulation could be started then, but the body is still kind of recovering from that initial stimulation. So, when time is not of the essence, we

would delay the start of the next cycle for most undergoing this type of treatment. It can be sped up and sometimes we can do more than one cycle, but you're right, in most cases really it's one cycle that we're able to fit in before starting the chemotherapy or the next step because again, the priority is on treating the cancer. We want to of course be mindful of this process and give it priority and the ability to do so if able, but the first and foremost is treating the cancer and being healthy.

Melissa:

I'm just finding this juxtaposition between these medical miracles that can be available to us and like you said, or the whiplash that ... And even when somebody doesn't take fertility into the equation, we know that very often people get through their cancer experience and then the emotional impact happens when someone is considered a survivor. It's the same thing. I wish we had more time to talk. There was one other question that was asked, which allows me to transition to the next part of our evening. Someone asked if there's a list of resources available somewhere. I can take that one. We will include some resources in a follow-up e-blast next week, including links to our program partners' websites. You can also check out the Sharsheret website where you have a wide variety of resources. We also have a PGT kit. It's a free kit that you can order. It includes resources and gifts that you will find helpful during this fertility journey. There are links for both of those in the chat box now.

Sharsheret also partners with the Jewish Fertility Foundation to offer an Oncofertility Support Group, which is a very unique thing to find. More information can be found with a link right there. Just went in right now. Thank you. Additionally, all of these things you can request more information about when you fill out the evaluation. So, before we break into two brief sessions that I mentioned at the start of the evening, I am really excited to be able to announce an exciting new program and partnership. We are thrilled. We are absolutely thrilled to announce a new partnership with the Stardust Foundation, an organization dedicated to helping Jewish individuals. I'm just going to share my screen for a second. Jewish individuals and couples overcome financial barriers to building their families through grants and supportive resources.

This is a new exclusive collaboration. Eligible Sharsheret callers diagnosed with breast or ovarian cancer may qualify for grants of up to $5,000 to help cover egg and embryo freezing expenses. So, we're going to send more information out about this in the follow-up e-blast, but you can take a second as I finish up to just look at what is on the screen right now. I really want to thank Dr. Ressler, Dvora Entin for sharing not only their expertise, but clearly their passions. I found the presentation not only educational, but really very hopeful and I hope all of you did too. I want to thank Chloe and Ashley. You were so gracious to share your personal stories with us tonight. Thank you to tonight's sponsors, Basser, Lilly, Merck, Novartis, and the Cooperative Agreement 240061 of the Centers for Disease Control and Prevention.

Thank you to our amazing program partners, Illume Fertility, I Was Supposed To Have A Baby, Jewish Fertility Foundation, the Misconceptions Podcast. Shout out to that title, very clever. The Startups Foundation and Yesh Tikva. We are putting a link to an evaluation in the chat right now. We're going to give you an option, an opportunity to go into these groups. Please click the link before you go into the groups. Not only are there a couple of evaluation questions, but there are boxes to check to get more information about the Stardust Partnership, to learn more about

our Oncofertility Support Groups, to talk to one of our genetic counselors, to order our PGT kit and so on and so forth. So please, that link is going in right now.

I want to make sure. Did it go in? Because I didn't see it. It did go in. Okay, great. So please click it now and remember that Sharsheret social workers and our genetic counselors are there for you to answer questions, share resources, provide support. You can reach them through the link in the chat box now, but again, you'll be able to do that through the evaluation. I'm going to stay in the main room now in case someone has a question or a technical issue, but we are about to launch two rooms. You choose which room makes sense for you. The webinar will end after these two breakouts. So, in advance, I want to wish you a good night and thank you for joining us.