

# Real Talk with the Boobie Docs & Sharsheret: Genetics, Risk, and Resilience

National Webinar Transcript

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Presented by:



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## 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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## Real Talk with the Boobie Docs & Sharsheret: Genetics, Risk, and Resilience

Ellen Kleinhaus:

Okay. Let's begin. Welcome and thank you for joining us for tonight's webinar, *Real Talk with the Boobie Docs & Sharsheret: Genetics, Risk, and Resilience* with Dr. Robyn Roth and Sharsheret's genetic counselor, Bianca Haser. I am Ellen Kleinhaus, Director of National Outreach at Sharsheret and an AEPi sister from the Phi Mu chapter. Sharsheret is also in the midst of our summit, which brings together thousands of people for virtual and in-person education all across the country. Please visit our Sharsheret Summit website to learn more and to sign up for any of our upcoming webinars today through October 31st that feature top experts in the field. My colleague is going to put the link in the chat.

Tonight's webinar is in partnership with AEPi's, *The Next Chapter*, and I would like to thank all of the AEPi sisters and alumni for attending and supporting Sharsheret. Special shout out to Erin, Jen, Mary, and Bonnie for making tonight happen. The webinar is also sponsored by AstraZeneca, the Basser Center for BRCA, and the Cooperative Agreement 24-0061 from the Center of Disease Control and Prevention. Before we begin, a few housekeeping items. Tonight's webinar is being recorded and will be posted on Sharsheret's website along with a transcript. Participants' faces and names will not be in the recording. If you would like to remain private, you have the option to turn off your video and rename yourself, or you can call into the webinar.

We also have closed caption available. To display live captions on the bottom bar, click on the captions and then click on show captions. You may have noticed that you were muted upon entering the Zoom. Please stay muted during the call. We will hold a Q&A at the end of the presentation. If you have any questions, please type them in the chat box, and we will get to as many as we can during the Q&A. I want to remind you that Sharsheret is a not-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. Our full medical disclaimer is in the chat.

A quick program spotlight, if you're interested in giving back to Sharsheret, we're looking for new bakers to join our annual Pies for Prevention Thanksgiving Bake Sale, supporting the Stephanie Sussman and Ann Nadrich Memorial Jewel and Sharsheret's Ovarian Cancer Program. You can become a baker and bake alongside over 25 sales across the country. Visit our website to learn more and sign up.

Most importantly, if you are at increased risk for hereditary cancer, currently facing a breast cancer or a varying cancer diagnosis, please remember that Sharsheret is here for you and your loved ones. Sharsheret provides emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience. All are completely free and confidential, and our contact information is now in the chat box. If you are interested in bringing Sharsheret to your community and partnering with other AEPi alumnae or have any other questions, please reach out and we will get you started. As the Sharsheret AEPi liaison, my contact information is in the chat box.

Now, before we welcome Dr. Roth and Bianca Haser to the screen, I am pleased to welcome Shira to share her story. Shira is an AEPHI alumnae from American University Epsilon Theta Chapter, class of 2005. Thank you for being here and welcome.

Shira:

Hi, thank you so much for having me. So I'm here to share my story. In 2006, my sister Shari was diagnosed with breast cancer at the young age of 28 years old. And so, at the time, the doctors and everyone started asking about family history, and we didn't really have any long line of family history, but they said that at such a young age, it's most likely genetic, so she was tested for BRCA and found that she had the mutation. I was only 23 years old, but I decided I wanted to get tested. And so, I found out that I had the BRCA1 mutation back in 2007. So ever since 2007, I've been really diligent about getting my mammograms and MRIs. I would get each once a year, six months apart, so I was being screened every six months, starting in 2007.

So fast-forward to 2023 was my last mammogram or MRI before I got pregnant with my first son. And so then, I had to take a little break to go through pregnancy and then breastfeeding. So my very first MRI back after about two years of not being screened was this past March, March of 2025. I just had this gut feeling the night before. I said to my husband, "This is the time," and he looked at me, and he's like, "You're crazy. You're just getting nervous and anxious because it's been two years. You had the baby. You couldn't go in the MRI machine and this and that." I was like, "I'm telling you, this is the plan. This is how it works. They let me get married, they let me have my kid, and now, this is what's going to happen." I just had that feeling, and I was correct.

So I was diagnosed with stage one breast cancer this past March, and in April, I had a double mastectomy, and then everything was going really smoothly and had really a pretty easy recovery from the mastectomy for the first three to four weeks. And then, unfortunately, I ended up with an infection. So I ended up back in the hospital and had to have a second surgery called a debridement. And then, after I recovered from that, I started my chemotherapy treatments in June and did all my chemotherapy over the summer. I had my last chemo last month in September, so I got to ring the bell, and I'm officially cancer free. Yay. And so, now, we just have the last steps of reconstruction, and also, I'm choosing to also have my ovaries removed since I am a BRCA1 mutation carrier. After going through all of this, I'm a very optimistic person and happy, but I don't want to go through it again, so we want to get the ovaries taken out as well. So those surgeries are happening this December.

And then, I just wanted to speak quickly about how Sharsheret has played a role in all of this and has helped me. So literally, in the very first week of being diagnosed back in March, I reached out to Sharsheret and right away, they had a social worker on the phone with me to see how I was doing emotionally. They sent tons of information but also treats, asked the ages of my child and my stepchildren, and sent tons of gifts and fun things for them to keep their mind off of the diagnosis. And then, there's a support group on Facebook that I've been very active in, and that has been a really, really nice community to ask questions and get support. Complete random strangers through Sharsheret sent me different kinds of bras for the surgery and drains, bags for showering. All these people just kind of reached out when I shared an Amazon list and said, "I'm about to buy these things." I was like, "Is this the right stuff that I need before mastectomy?"

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And instead, all these people messaged me back asking for my address and sent me things, so it's been a really sweet and warm community. And then, during the chemotherapy, I decided I wanted to try the cold capping, which is a way to help preserve your hair, and it's not usually covered by insurance. So that is something that Sharsheret also was able to grant me to pay for that. Unfortunately, didn't work so well, and I ended up shaving off the rest of my hair, but it's starting to grow back as you can maybe see, so that's nice. But also, when I don't want to look like this and I want to have a wig, Sharsheret also provided a real hair wig for me. So there's just been a lot of things through Sharsheret, both financially and community support, so it's been really awesome to have their support through these past six months and have really felt loved and felt the community through this time. And thanks for having me tonight, and I'm looking forward to hearing the presentation.

Ellen Kleinhaus:

Shira, that was beautiful. I was totally blown away, and thank you so much for sharing. Congratulations on ringing the bell.

Shira:

Thank you.

Ellen Kleinhaus:

Excited about that as well. It's really, really fantastic. It's also really important because sharing your story and stories like these really make an impact and really make a difference tonight to bring that personal experience to all the work that we do. So really, really thank you and kudos to you.

We are honored to be joined tonight this evening by Dr. Robyn Roth. She recently shared with me that although she's not an AEPi sister, her real sister is and her sister-in-law is, and she has many friends who are AEPi, so she is definitely excited to talk to the group. She is an Ivy League-trained board-certified radiologist specializing in breast and abdominal imaging. Over 25,000 of her closest friends call her at the Boobies Docs, her popular social media platform where she discusses breast cancer and breast health in an educational and fun way. So if you don't follow her, you should. Aside from being a breast cancer specialist, she is a 40-something Ashkenazi Jewish woman with a strong family history of breast cancer and genetic mutations, so she advocates and empowers about the importance of early breast cancer detection and understanding your risk factors.

Dr. Roth hosts a podcast, the Girlfriend's Guide to Breast Cancer, Breast Health, & Beyond to help those navigating a breast cancer diagnosis, and it's available on all podcast platforms. She's also a content creator, educator, media contributor, and breast cancer advocate. She lives in southern New Jersey with her husband and three children, and she's hosting her annual Boobie Bash Masquerade on Saturday, October 26, at the Legacy Club in Cherry Hill, New Jersey. So I guess that means if you want to go, you need to connect with her. So without further ado, it's really my pleasure to introduce Dr. Robyn Roth.

Dr. Robyn Roth:

Thank you so much. I just want to mention that me not being an AEPi sister was not by my choice. I did not get in, and I really desperately wanted to, but I didn't rush again at UF, but it's fine. I think this makes me an honorary member by doing this talk tonight, so I'm happy to be here. Let me thank you for a beautiful introduction. I hate to inform you. I don't know why... We actually had the Boobie Best last weekend, so you can't come. I don't know. I had the dates wrong I guess in the other one, but let me pull up my PowerPoint. And Shira, your story was so beautiful, and it really resonates so much with what I'm going to be talking about tonight because similar story with my cousins, and I want to share that. Let me just pull up my presentation. Let's see. Share.

Okay, so I'm going to try not to talk too much about the genes because I know Bianca's here and she's going to do that better than I will. I really want to talk a lot about the screening and why this is so important to me. So like she mentioned, I have a platform, the Boobie Docs, and it's plural because I used to do this with my best friend who's also a breast radiologist who worked with me, but she doesn't like social media, but I keep the S. Maybe one day she'll be back. I went to University of Florida, where I was not a member of AEPi. I was a member of A Chi O. Again, I think I went to every date function, and people even in the sorority think I was in the sorority because I was at every date function.

I went to Albert Einstein College of Medicine in New York, and then I went to Penn for my radiology residency and breast imaging fellowship. I'm a breast radiologist in Cherry Hill, New Jersey. If anyone is familiar with South Jersey, it's right outside Philly. I'm really passionate about, like she said, about early breast cancer detection and myth busting. I'm a mom of three kids. This was actually out to the Boobie Bash last week. They're five, eight, and 10, and they're awesome. So these are my cousins, Melanie and Michelle, and this is my sister Brooke, who was an AEPi member at UF. She graduated, I think, '07. So this was at her wedding, well, her first wedding. So those are my cousins, Melanie, Michelle, and back when I was in med school and they were in their early 30s, Melanie, the younger one on the left of the picture, she felt a lump in her breast, and she went to a radiologist who said, "It's probably benign. Don't worry about it."

She's like, "Well, I'm worried about it. I want you to do a biopsy." And lo and behold, it ended up being triple-negative breast cancer, and this was probably early 2000s, so before Angelina Jolie effect, before we talked about genetic mutations like we do now. And so, she was going down the road of having a lumpectomy. I think she already had the lumpectomy and they were about to start radiation, but then her friend had heard of a test that lived in New York, and she's like, "You should get tested for BRCA." So she gets tested, and lo and behold, she's positive. She has the BRCA2 mutation. So then, her sister, Michelle, who is two or three years older than her, decides that she needs to go get a mammogram, and she is now 35. She has breast cancer in a lymph node, and she has BRCA2 positive as well.

And this was like a spontaneous mutation in the family line. There was no history of breast cancer up to this point. And thankfully, I think it stopped there at least for me and my sister. My mom and their dad or brother and sister, we've been negative so far. She has an 18-year-old

daughter though and a 21-year-old son who do need to be tested, and they're waiting for the right time, and that's an interesting question about when you should be genetic testing, which I have some thoughts on which we can talk about. So why is it so important? Why does it feel like all these Jewish people have genetic mutations? Well, we do because people of Ashkenazi Jewish descent, which are Eastern and Central European ancestry have a 10 times higher likelihood of carrying specific BRCA1 and BRCA2 gene mutations, which increases your risk of breast, ovarian, prostate, pancreatic cancer, and melanoma.

It's not just women. It's men as well, and that's an important point. And why does it feel like all Jewish people have this? Because of the founder effect, because we like to marry Jewish people, so that's why we keep it in the family. So the risk in the general population is about 1 in 400 people carry a BRCA mutation. Ashkenazi Jews is about 1 in 40, so 10 times higher than the general public carry one of three specific founder mutations, men included. I ended up changing the sign because it said 1 in 40 Ashkenazi Jewish women, but it should be all people. It doesn't matter your sex.

So I know you know your sister, Jill Martin, had a story similar where she... This was also on the Today Show. You can't see my sign, but it said, "Today's a great day to get genetic testing." I was actually there with Jen Feldman who's on the call as well. So her mom and grandma had breast cancer, and their genetic testing was negative, so she kind of walked around her whole life thinking she was negative. But then, in her mid to late 40s, she realized she'd never been tested, and she ended up being BRCA2 positive, which she inherited from her dad, so she decided to get a prophylactic mastectomy. They did an MRI before her prophylactic mastectomy, and unfortunately, they found early, but aggressive breast cancer.

So again, if it wasn't caught on this MRI, if left undiagnosed, it could've potentially killed her. Her story is important because she had it relatively late, so had she known she had a BRCA mutation in her mid-20s to 30s is where we would like to know about that, she could have been aggressively screening. I don't think it would've changed anything except maybe made her have more anxiety throughout her life. But either way, she found out when she did. But again, it's not uncommon for someone to find out they have genetic mutation, but then also find out they have cancer at the same time.

So women with a BRCA1 or 2 mutations have up to 65 to 85% risk of breast cancer and a 15 to 45% risk of developing ovarian cancer. Men with these mutations have increased risk for male breast cancer as well as prostate cancer and pancreatic cancer and melanoma. Because of the high prevalence, genetic testing is especially important preventative measure for those of Jewish ancestry even without a strong family history. It sounds like my case, and then Shira's case, there was no family history. They were just getting tested because they found breast cancer. We would like to do that before. Actually, here is me and Jen at the Today Show.

So who should be getting genetic screening? Well, if you're Jewish, Ashkenazi Jewish, then you should consider it because there could be silent mutations in your family as in these cases. Also, if you have a personal or family history of breast or ovarian, prostate cancer, or pancreatic cancer, especially if it's like a dad or if it's a premenopausal young breast cancer or a triple-

negative breast cancer, that's more likely, or if you have someone in your family that's known to carry a BRCA mutation and knowing which specific mutation that they have helps identify it in the testing. Bianca could speak to that a little bit more probably.

So testing is really simple. I've done it twice now, most recently, a few months ago, and it's easy as fitting into a vial and sending off your saliva. And so, you could test for three Ashkenazi Jewish founder mutations, but if you're going to test, you should just test for everything, the comprehensive panel, which includes other cancer-causing genes that, again, because we keep it in the family, we have a founder effect. There's a lot of genetic mutations being passed around our gene pool, such as PALB2, CHEK2, ATM, Li-Fraumeni, just to name a few. So there's a whole host. Everyone thinks of BRCA1 and 2, but there is a lot of cancer-causing genes unfortunately that we can test for now. And even if your testing is over 5 to 10 years old, you probably want to reconsider doing it again because genetic mutation, they find new ones all the time, and it's growing constantly. It's really important if you're going to get genetic testing, you get genetic counseling as well before and after to interpret what the results mean for you and your family and to plan the next step.

So when should you get testing? Well, that's a very personal question, and it really depends on where you are in your life and where you are in your fertility journey, also, I think comes into play. We wouldn't really do anything before age 25. We wouldn't really do any screening. Most people would not recommend a prophylactic oophorectomy at that age. So if you're not going to do anything with the information, then you might want to wait. Typically, start having a conversation at 25, I'd say. That's when you're going to start having screening. It sounds like Shira did a little bit earlier, which is fine, but if a 23-year-old finds out that they have an 85% chance of developing breast cancer in her lifetime, they might act... I don't know. You could see them doing... I don't know.

They may not be ready to handle that information, so it is a big pill to swallow. Even if it's positive, the guilt that comes with that or just the mourning what you thought you had. But also, if you're negative, there's also a guilt that you don't carry it when other family members do. So it is complex, and it's something that needs to be taken seriously, and genetic counseling is so important. So what if you're positive? What if do you have a genetic mutation? Well, knowledge is power, right? There are so many things that we can do. We can start your cancer screening earlier and more often so that we could find your breast cancer at an early stage. Shira is a perfect example. We usually start MRI at age 25 and then add on a mammogram beginning at age 30, kind of alternating every six months. You're never going more than six months without imaging.

You actually can get mammograms while you're pregnant. You really can't get MRI when you're pregnant, but you can get mammograms when you're pregnant and ultrasound, and both of them, actually, mammogram, ultrasound, and MRI, you could do when you're breastfeeding as well. It is important to mention that breast cancer is the most common cancer during pregnancy and breastfeeding, so it's always just really important to take your breast health seriously even when you're pregnant. A lot of times you'll feel lumps, and it's just milk, but you just want to

make sure that it's just that. And I always tell people we just don't want to assume that it's just a clogged up without really doing the appropriate workout.

If you find out you're positive, you could also do risk reduction strategies like a prophylactic mastectomy or medications like tamoxifen or having your ovaries taken out to lower your risk of developing ovarian cancer. It does bring up the conversation of fertility preservation. If you don't have a family or all the children you'd like to have, then maybe you want to freeze your eggs beforehand so that you could potentially use a surrogate. And then, it helps encourage other family members to get tested, too. If you find out you're positive, then it might encourage your dad who's never thought about it a day in his life to go get tested and find out that he might be at risk. Did you know that Bey once's dad is BRCA2 positive and had breast cancer as well? So fun fact.

A lot of people have family history of breast cancer, but they don't have a known genetic mutation. It runs in families like it's passed in... There are genes we don't know about yet, but having one first-degree relative that's diagnosed with breast cancer essentially doubles your risk. Having two or more first-degree relatives who are diagnosed with breast cancer increases your risk by three to four times. It is a higher risk if your first-degree relative was diagnosed at a young age, so premenopausal breast cancer, so usually before age 50 or had bilateral or triple-negative breast cancer, then you're more likely to carry a genetic mutation as well. If you are old enough to remember family matters, then you're old enough to get a mammogram.

The bad news is that 85% of people that are diagnosed with breast cancer have no known family history or genetic mutation. The two greatest risks for breast cancer are being female and getting older. So, by definition, we are all at risk, and this is Debbie Downer. I always like to make that joke because it's true, but men, too. Men have breasts. They are not screened routinely, but they are at risk for breast cancer as well.

So, this is a recommendation from the American College of Radiology that I try to really bring to people's attention. So, all women, especially black and Ashkenazi Jewish women, should be evaluated for breast cancer risk by age 30, ideally beginning at age 25. So those that are at higher risk can be identified and benefit from starting breast cancer screening early because if you have a greater than 20% lifetime risk of breast cancer, then starting age 40 is way too late. So, it's really easy to find out your breast cancer risk. Obviously, it's best done with a healthcare professional, but you could easily do it online by Googling something called the Tyrer-Cuzick Risk Calculator. It's very easy. You plug in your age, your BMI, your height, your weight, when your first child was. Having a first child after the age of 30 is a risk factor for developing breast cancer, so we are seeing that more and more with women postponing childbirth.

Also, breast density, if you know it, goes into play. If you've ever had a prior biopsy or if anyone in your family has ovarian cancer, and then a very detailed family history, not just first-degree relatives, but also second and third-degree relatives. It adds up, not as much as a first degree relative. The take home message is that genetic screening can be lifesaving for people of Ashkenazi Jewish descent. Even in the absence of family history, testing is encouraged because

early knowledge allows for proactive prevention, tailored screening, and family awareness. But most people diagnosed with breast cancer have no known family history or genetic mutation.

I also want to mention that even if you're regular risk, if you're average risk, which is about 12% over your lifetime, you still want to do mammography beginning at age 40. And then, if you have dense breast tissue, you really want to consider adding an ultrasound or MRI depending on your risk factors. But I will also say that I would really strongly encourage a monthly self-breast exam because we are seeing a rise in young breast cancer. Many of the people do not have known genetic mutations or the risk factors we're typically looking for, and they're not routinely being screened. And about 80% of young women that are diagnosed with breast cancer are finding it themselves, so it's really just important to be breast self-aware and get to know how they look and feel normally, so you could recognize the change.

That is... Oops. Oh, I had that last slide I wanted to show. Oh, no. How did I do this? It's supposed to say, "Let's be breasties." I don't know where that went. So you could follow me on social media at The Boobie Docs. I also have a children's book coming out called Everyone Has Boobies. That is me as a cartoon character. I'm really excited about that, and my kids are in the book, and it's really cute, so I am excited for all of it. I believe I'm going to include a list of resources, and I'm probably going to include Sharsheret and I want to talk to you guys off about that offline because I want to make sure I have resources for parents that are diagnosed with breast cancer and cancer in general. So thank you for having me tonight and making me an honorary AEPi sister for the night.

Ellen Kleinhaus:

Well, thank you, Dr. Roth. This was great. Excited that we're adding author to your long list of accomplishments. So congrats to you on that, and really thank you for sharing so much information. Every time I follow you and I see a new post or I hear you speak, I really learn so much and something new-

Dr. Robyn Roth:

Thank you.

Ellen Kleinhaus:

... so thank you.

Dr. Robyn Roth:

Thank you.

Ellen Kleinhaus:

I'm now going to introduce Bianca Haser, Sharsheret's Genetics program coordinator, a graduate of Sarah Lawrence College with a Master of Science in genetic counseling. At Sharsheret, Bianca consults with women and families and answers individual questions about their family histories, BRCA, and other genetic mutations, personal risks of hereditary ovarian cancer, and contributes to the development and implementation of Sharsheret's hereditary cancer resources and programs. Welcome, Bianca.

Bianca Haser:

Thank you, Ellen. And thank you so much, Shira, for telling your story. It's really important for other women to hear it from people who go through it themselves, and thank you Dr. Roth for all of the important points you brought up. I am going to speak a little bit more about cancer and genetics and really just reiterate all of the important points that Dr. Roth spoke about because knowing this information is really important for protecting your health. First slide can go. Okay, so most of the cancers that we see, they do just happen by chance, so not due to one specific genetic mutation, but more often due to a combination of genetic factors, environmental factors, lifestyle factors, breast cancer, like Dr. Roth said, being female and getting older is the biggest risk factor, but we do know that about 5 to 10% of breast cancers and about 10 to 15% of ovarian cancers are due to gene mutation that is inherited. So really understanding your genetic risk is so important in guiding you and your healthcare team on cancer screening decisions and preventative options.

As Dr. Roth mentioned, there are certain founder mutations in the Ashkenazi Jewish population that are more common and put them at a much higher risk for certain cancers. Next slide. So again, 1 in 40 Ashkenazi Jewish men and women carry a mutation in the BRCA1 or BRCA2 gene. And like Dr. Roth said, when you compare this to the 1 in 400 general population risk, you see that it's 10 times higher, so it's a significantly higher risk than the average person. We also know that in Sephardic and Mizrahi Jews, they carry an elevated risk as well, most likely due to the intermarrying between the two populations. We don't have as concrete data or numbers on their risk, but we know it's higher than the general population risk. Next slide.

So mutations in the BRCA1 and BRCA2 genes carry up to a 80% lifetime risk for breast cancer and between a 15 to 50% risk for ovarian cancer depending on the gene and the mutation. You can really see the significance of this risk in this graph that's here. So the pink are the individuals who have a BRCA mutation, and when you compare it to the general population risk, which is in the gray, it's just so much higher. So just to put it into context, the average women's risk for breast cancer falls at about 12% lifetime risk, and for ovarian cancer, the risk is somewhere between one to 2%. There's also an increased risk for prostate cancer in men, pancreatic cancer, and melanoma, so this by no means affects only women, but the difference is much higher in women, for sure.

Anyone who carries this mutation also has a 50% chance of passing one of these mutations onto the next generation, and that 50% risk is for every pregnancy. It's also important to be aware that there are other genes that can cause an increased risk for cancer, and most of the testing that's done now is through a multi-gene panel test, so it'll often test for other breast and ovarian cancerous genes like ATM, PALB2, CHEK2. You may also be tested for other cancer risk. Lynch syndrome genes for colon cancer is another big one. Next slide.

So who should have genetic counseling and testing? Again, Ashkenazi Jews should have testing even if there is no family history and no significant family history as we heard in Shira's story. But we often see women in the clinic who will test positive for BRCA1 or BRCA2 gene mutation even if there's no family history that they're aware of, and it could be due to the fact that maybe it's a small family size, so we don't see any of the patterns there that we may expect, or it could

be due to just having more males in the family than females. And so, we're not seeing that breast and ovarian cancer that we might see if there were more females in the family.

Other things to look out for in the family history are cancer diagnoses at a young age. So under the age of 50 is when we start to think maybe there could be genetic cause behind this that's driving this cancer. More rare cancers being diagnosed in the family, so things like ovarian cancer, pancreatic cancer, male breast cancer is definitely an indication for genetic testing as well. And then, we also just want to be aware of any patterns of the same or related cancer through multiple generations in the family. There are definitely other indications for testing. This is a good overview, but it's also really just important to note that having... Sorry, next slide.

Thanks. So it is really important to note that having the test is optional, and seeing a genetic counselor can really help guide you in deciding which test is right for you and the timing of the testing. So like Dr. Roth explained, often, we won't change anything in the screening or management options that we're offering to an individual until they turn 25. And so, we often may recommend waiting or beginning testing as you get closer to the age of 25 because for example, if somebody tests positive for a BRCA1 or 2 mutation, that's when we would recommend having a breast MRI done annually, so testing around that age usually makes sense. Other things that genetic counselors can be there for is just explaining the benefits and limitations of testing their implications with health insurance, life insurance that everyone should be made aware of with before going through with the testing.

They can also really help you understand what your results mean to you and your family in an individual case. So sometimes or fairly often, we get women who will test negative, sorry, but just based on the family history or the personal history, they can still be considered high risk, so we may still then recommend additional screening and surveillance options. Genetic counselors are also really there to discuss what this means for other family members, and how to bring this up with your siblings, cousins, and children as well. Next slide.

So what does it mean to get a positive result? This is a question that often brings up a lot of feelings of fear and anxiety in people that might prevent them or delay them from getting testing, but it's really important to remember that the genes that are tested for in these multi-gene panel tests are often actionable. So that means that if you test positive, you can take steps to manage your health and really protect yourself. So depending on the gene, recommendations may include increased surveillance, so like we've discussed with the BRCA mutations, beginning of breast MRI at age 25 typically and then adding on the mammogram at age 30 and having those both done every single year, spread apart by six months, so that you're being watched as closely as possible for any cancers that may be developing. This is really in contrast to the general recommendation where you would begin mammograms at age 40.

A positive result may also bring up conversations about medications that can reduce the risk for getting cancer and preventative surgeries like having a prophylactic bilateral mastectomy, having the breast removed preventatively, or having the ovaries and fallopian tubes removed as well to really reduce the risk of getting cancer in the first place. It's also really important to note that the option of preventing this from going to the next generation by doing IVF with pre-implantation genetic testing. So testing the embryos to see which ones don't carry the mutation that you carry and then implanting those, it's definitely not something everyone will do. It's expensive, it's emotionally draining, but it is an option out there and something that will be brought off if somebody tests positive and is considering family planning in the future. Next

slide. Okay, so that's it. So if you have any personal questions about genetics or your family history, please reach out to us. We're here to help guide you through any of your questions. Thank you.

Ellen Kleinhaus:

Thank you, Bianca. That was really terrific and informative as well. Again, always learn something new. I do want to share that Sharsheret has two genetic counselors on staff. Consultations with them are free and confidential, and they are a wealth of information. I know from a personal perspective, so I really encourage everyone, if you have a question, no question's a silly question. They're there to help and really answer. So thank you so much.

I'm now going to lead the Q&A portion. If anyone has any questions, feel free to post them in the chat, or you can send us the question privately if you're more comfortable with that. Please remember though that we cannot address questions that reference any type of personal situation. That is something that we can do offline at another time. So I guess Dr. Roth, I'm going to ask you because I had a few questions that came in earlier, so we'll go with those first. I wonder if you could talk a little bit about lifestyle and its impact. Can you talk a little about diet, exercise, alcohol, that type of decisions people are making going forward and what they're doing every day?

Dr. Robyn Roth:

They estimate that about 30% of breast cancers are caused by modifiable risk factors, so lifestyle factors that we have control over. When we talk about breast cancer risk, there's non-modifiable, so things that you can't change like your genetics, being female, getting older, and then there's modifiable ones. I like to give people these five healthy lifestyle tips that you can do to lower your risk of developing breast cancer, which are maintaining a healthy weight, exercising at least 30 minutes a day, minimizing alcohol. Unfortunately, there's no safe level of alcohol, and it increases the risk of breast cancer, but many cancers, unfortunately, smoking, no smoking, and then also having a plant-forward diet that is rich in leafy green, fibrous vegetables as well and avoiding processed foods. Another one is actually having normal vitamin D levels. That's one we don't talk about much, but studies have shown that it improves your outcomes and lowers the risk of developing breast cancer.

But that being said, I know many people who do everything right on paper and still develop breast cancer. So I like to say it doesn't prevent breast cancer, but it does lower your risk and improves your outcomes if you're diagnosed, so it is worth doing. But screening does play such an essential role because like I said, there's so many things are out of our control, environmental factors, the microplastics in our packaging, I could go on and on and on. So not just freak everybody out, but I do think that there are some things that we can do to lower risk, but still, screening is so important.

Ellen Kleinhaus:

Okay, great. Thank you. Another question for Bianca. How do you approach testing in families where people might be kind of hesitant or afraid to find out their results?

Bianca Haser:

Okay, so genetic testing can first of all bring up so many different emotions, and even if someone's in the same family, they can have conflicting feelings. Some people may feel fear or anxiety, and for others, it could be feelings of guilt. As a genetic counselor, my job is to just provide the information in a clear, informative, unbiased way. And then, as a patient's job, if you test positive, it is your job to inform the family members, but you can't convince them to get testing. As a genetic counselor, I can provide people with resources and discuss ways to approach the subject with family members, and it's going to be really case-by-case individual basis, but yeah, that's mostly it.

Ellen Kleinhaus:

Great, thank you. I guess this can go to each of you. You can both answer the question. What's one message that you hope everyone will take away from tonight? You shared so many important pieces, but if you had one call to action or one nugget, what would it be that you would want to share? Dr. Roth, we'll start with you.

Dr. Robyn Roth:

You're not too young to get breast cancer. Take it seriously.

Ellen Kleinhaus:

Yeah.

Bianca Haser:

For me, it would be knowing your genetics and your family history can really help you make the informed decisions for your own healthcare.

Ellen Kleinhaus:

I love those. Thank you. Those were great.

Bianca Haser:

Thank you.

Ellen Kleinhaus:

And last question, I don't think we have anything in the chat. Again, I'll put it out to both of you. What is one practical step that each of us can take here on the screen this month, being the end of breast cancer awareness month, that can help protect us for breast or ovarian health?

Dr. Robyn Roth:

I would say do a self breast exam and make sure you're up-to-date on your breast cancer screening. Not just a mammogram, but also ultrasound or MRI if you're gents or have risk factors.

Bianca Haser:

I would say learn your family history if you can, and ask your doctor, your gynecologist to evaluate what your risk is for cancer.

Dr. Robyn Roth:

I want to also mention one more thing is that early detection is the breast protection. Breast cancer is very treatable when we find it early. When it's localized to the breast, survival rates are greater than 99%, so that's what we're going for, and that's why I think sometimes I feel like it's only a matter of time before I develop breast cancer. That's just what I see in my practice, but my goal is really to catch it early, and then it's so much more treatable than it is if it's late stage. Of course, drug treatments are improving all the time, even for late-stage cancers, but that being said, early detection is the breast protection that's going to go on my tombstone.

Ellen Kleinhaus:

I love that. Thank you so much to both of you.

Dr. Robyn Roth:

Thank you.

Ellen Kleinhaus:

Really great messages. I think it was really important for you to be able to share with the sisters of AEPHi, and really, I think it gives everyone a little bit of food for thought and knowledge, and as we all know, education is really empowering, so thank you both for sharing tonight. Oh, can you post the email addresses for questions again? Yes. So we will do that in the chat, of course.

Dr. Robyn Roth:

My DMs are always open, too. They can't see. I'm blocking my thing, but yeah, my DMs are always open, and my children are attacking me now.

Ellen Kleinhaus:

All good. All good. Okay. As we begin to wrap up, please take a moment to fill out a brief evaluation survey that is also going to be put in the chat. It really informs Sharsheret's overall future programming. Thank you again to Shira for sharing her personal experience, to Dr. Robyn Roth, also known as the Boobie Doc, the cuties are in the background, and our Sharsheret's own Bianca Haser. Tonight's webinar was in partnership with AEPHi, The Next Chapter, and sponsored by AstraZeneca, the Bassler Center for BRCA, and the Cooperative Agreement 24-0061 from the Centers of Disease Control and Prevention.

Please remember that Sharsheret is here for you and your loved ones. Sharsheret provides emotional support, mental health counseling, and other programs designed to help navigate you through the cancer experience. All are completely free and confidential, and our contact information is in the chat box below. Once again, please, you could fill out the survey. We're going to post that one more time. I just want to thank AEPHi for being a partner of Sharsheret and for allowing Sharsheret to be one of your philanthropies. Really, together, we know that we're making a difference. So thank you, everyone, and have a great night.