Do I Need to Take Out My Ovaries

National Webinar Transcript

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Presented by:

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Elana Silber:

Name is Elana Silber and I am the CEO of Sharsheret, and I want to thank everyone for joining us this evening for our latest in our webinar series, Do I Need to Take Out My Ovaries? Before we begin, we're grateful to tonight's webinar sponsors, Eisai, Gilead, ImmunoGen and Novocure. And thank you to

Sharsheret Summit sponsors, Merck, GSK, Daiichi-Sankyo, Lilly, Seagen, Pfizer, AstraZeneca, and Natera. So just a few housekeeping items. Today's webinar is being recorded and it will be posted on Sharsheret's website along with the transcript. Participants' faces and names will not be in the recording. If you want to remain private, you can turn off your video and rename yourself or you can just call into the webinar. There are instructions in the chat box now for both of those options. You also may have noticed that you were muted upon entering the webinar.

Please keep yourself on mute throughout the presentation. If you have questions, you can put them in the chat box either publicly or click on Sharsheret in the chat box and submit a private question. We happen to received many, many questions in advance of this webinar. This is really a hot topic and we anticipate receiving many questions in the chat box. We're going to do our very best to answer all your questions, but rest assured if any questions are not answered tonight, we will address them by email over the next week. We also recommend that you keep your screen on speaker view. This will enable you to see the doctor's presentations and you can find that option in the upper right-hand corner of your screen. Before we hear from the presenters this evening, we do have a quick message from our sponsor.

This September for National Ovarian Cancer Awareness Month, ImmunoGen is highlighting the importance of biomarker testing. Biomarkers are features found with cancer cells that can make them different from other types of cells. Testing for biomarkers may help your doctor identify an appropriate therapy for you. If you have ovarian cancer, the following biomarkers could inform your eligibility for FDA approved therapies in ovarian cancer, breast cancer gene, BRCA, folate receptor alpha, FRa, genomic loss of heterozygosity, GLOH, homologous recombination deficiency, HRD. Talk to your doctor about testing for these and other relevant biomarkers. And remember, Sharsheret does not provide any medical advice or perform any medical procedures. We do not endorse or promote any specific medication, treatment, testing, product or service. The information provided this evening is not a substitute for professional medical advice or treatment. You should always seek the advice of your physician or other qualified health provider.

In a moment, I'm going to introduce you to our amazing presenters this evening. They will give their presentations and followed by a Q and A. After that, we will immediately begin our special bonus breakout program with the Embrace group, those facing metastatic breast cancer or advanced ovarian cancer, for an intimate private session with the doctors. And in conversation with Bonnie Beckoff, our director of support services. So this webinar topic for tonight was prompted by the recent statement by the Ovarian Cancer Research Alliance, the OCRA, recommending that those undergoing pelvic surgeries for other benign non-cancerous conditions, including hysterectomy, tubal ligations, cysts, endometriosis, should consider having their fallopian tubes removed as part of the already planned procedure. I can't tell you how many women have been approaching me over the last year, maybe year and a half, those who are at increased risk for cancer and those who are maybe just beyond the childbearing years wondering about this guidance.

Tonight we will address that question and more. We're really honored to be joined by incredible doctors, Dr. Melissa Frey, Dr. Haley Moss, and Dr. Deanna Gerber, all of whom happen to also be Ashkenazi Jewish, have Jewish Ashkenazi ancestry. Dr. Frey is an assistant professor of obstetrics and gynecology in the division of gynecologic oncology and the director of the Genetics and Personalized Cancer Prevention Program at Weill Cornell Medicine. Dr. Frey specializes in the management of hereditary cancer syndromes. Dr. Haley Moss is an assistant professor of obstetrics and gynecology at Duke Health specializing in gynecologic oncology and also cares for women who have a genetic predisposition for gynecologic cancers. Dr. Deanna Gerber is a clinical assistant professor department of obstetrics and gynecology at NYU Long Island School of Medicine and a gynecologic oncologist at NYU Langone. She also treats women who have been diagnosed with a genetic mutation that increase their

risk for gynecologic cancer. The doctor's full bios are available on our website. And now please turn your attention to Dr. Melissa Frey.

Dr. Melissa Frey:

Thanks so much. I'm going to share my screen. Can everyone see that? Great. Thank you very much for the invitation. I'm really excited to be here with two colleagues and truly close friends and Elana to talk about a topic that I am most passionate about. So let's start with ovarian cancer. Approximately 75% of people diagnosed with ovarian cancer are diagnosed in an advanced stage, and this is a tremendous problem because the rates of recurrence are quite high and rates of cure are very low. This begs the question, why are we not screening for ovarian cancer and finding it earlier in a stage one or stage two and screenings usually ultrasounds or CA125s? And unfortunately, the trials of these modalities have largely failed to show efficacy. And so currently ovarian cancer screening is not recommended because it just doesn't work. That's led to us rethinking the paradigm that ideally we can move away from treatment and towards prevention and trying to prevent more of these cancers so that we can prevent people being diagnosed with advanced stage disease.

So who's at risk? We know that probably about a quarter of ovarian cancers are actually caused by inherited genetic mutations. So many of you have heard of BRCA1 and 2, which are some of the largest contributors to ovarian cancer risk, but there are actually several other genes that now have a known increased risk for association with ovarian cancer. So three very important genes, RAD51C, RAD51D, and BRIP1, the Lynch syndrome genes. And Lynch syndrome is associated with other cancers as well like colon and uterine cancer, but also has an increased risk of ovarian cancer. And then two of the genes that have been most recently added to the list of ovarian cancer risk genes are PALB2 and ATM. How common are BRCA1 and 2 mutations? Well, we have to divide this question into the general population and the Ashkenazi Jewish population.

In the general population, about one in 400 people are affected with BRCA1 or 2, which is less than 1% of the population. But if you look at the Ashkenazi Jewish population, it's one in 40, so two and a half percent, which is really a staggering number. If you think about the number of Ashkenazi Jewish people you know or even the number that are on this call right now, that's a very, very high volume of likely of people that you know that are affected with BRCA1 and 2. Why is it important to diagnose these mutations? Well, we know that BRCA1 is associated with several cancers, breast, ovarian, and we're also learning more about pancreatic cancer risk, uterine cancer risk, prostate cancer risk. There's a free online risk assessment tool that I often use to help people think about risk. It's called ASK2ME.

And if we plug in a 25-year-old with a BRCA1 mutation, this is the lifetime risk that you would get. So the risk of both breast and ovarian cancer exceeds 60%. The risk of pancreatic cancer is lower with BRCA1, probably only about 5%. We could do the same for BRCA2 where we also see many of the same cancer risks. The breast cancer risk still quite high exceeding 60%. The ovarian cancer risk is a little bit lower, more in the 20 to 40% range, but the pancreatic cancer risk for BRCA2 is higher in many families approaching 10% lifetime risk. So how do we prevent this? I think we have to really think about the reproductive organs and the anatomy to understand the surgical options that are currently available. So this is the uterus, the cervix, the fallopian tubes, and the ovaries.

And the standard method that we use to prevent ovarian cancer is called bilateral salphingo-oophorectomy. This is removal of the fallopian tubes and the ovaries. For women with BRCA1, we recommend this at 35 to 40 years old, and that's because this is higher risk in people with BRCA1 and also the ovarian cancers tend to present earlier than BRCA2 for which we recommend taking out the tubes and ovaries sometime between the age of 40 and 45. If there's a cancer in the family at a younger age, then we may recommend this at a younger age. Unfortunately, taking out the fallopian tubes and

ovaries does result in surgical menopause. Some patients of will be candidates for hormone replacement therapy, but other patients, especially those who've had breast cancer, may have contraindications or patients with blood clots and may not be able to take hormone therapy.

Interestingly, there's a growing understanding that the majority of ovarian cancers were actually began as fallopian tube cancer. So it started in the fimbria and the fimbria you could see here is that edge of the fallopian tube. And this is important because it changes the way we think about cancer prevention. So if we remove just the fallopian tubes, that's called a risk reducing salpingectomy, we can we believe decrease the risk of ovarian cancer without causing surgical menopause because the ovary is the organ that makes estrogen and progesterone and so that organ remains intact without the fallopian tubes. The only thing that is really affected in a patient's life is that they cannot achieve a natural pregnancy because the egg cannot travel through the fallopian tubes, get fertilized, and arrive in a uterus, but people can get pregnant with assisted reproductive technology. So this preserves potential fertility and also hormone function.

As was mentioned earlier, the Ovarian Cancer Research Alliance put out a statement in January 30th of this year, which has gotten a lot of attention. So there's been growing research from this country, but also Europe and Canada that really suggests that removing the fallopian tubes decreases the risk for ovarian cancer. So based on this, the OCRA recommended that any woman who's undergoing a pelvic surgery for benign conditions, that would be a hysterectomy, a tubal ligation or sterilization procedure, removal of an ovarian cyst or endometriosis could consider at the same time removing her fallopian tubes. And this has been termed opportunistic salpingectomy. Of note here, these are people who are already planning to undergo surgery. So a question we get a lot is why can't everyone just take out their fallopian tubes? And I understand why people are asking that, but just to clarify, this statement really recommends this not as a sort of new surgery for no other reason, but for women who are undergoing a surgery for another indication already under anesthesia for an abdominal surgery. What about people with BRCA1 and 2 mutations?

Can they also get risk reducing salpingectomy? Do they have to have their ovaries removed? So my group has actually studied this, and this is a paper that we published earlier this year and first wanted to know, is this something that people with BRCA1 and 2 mutations are interested in? And we found that overwhelmingly yes, this is something that people are interested in learning about, interesting and taking advantage of if offered. And so what are the pros that people are reporting? Well, obviously avoiding surgical menopause, preserving fertility, allaying some people's concerns about sexual function and avoiding the need for hormone replacement. But people also note some important cons. There are concerns about safety and oncologic safety and then also concerns about surgical complications. For someone with a BRCA1 and 2 mutation, the question is not can they just have their fallopian tubes out?

It's really are they willing to have two surgeries, taking out the fallopian tubes and then at some point going back to remove the ovaries. And so I think many people understandably worry about two surgeries, two anesthesias and any increased risk of complications from that. Our gold standard in management for BRCA1 and 2 are NCCN or National Comprehensive Cancer Network Guidelines. And so I just want to show the most recent update. So you could see this is just released I think earlier this month. These are the 2024 guidelines and you can see that salpingectomy for people with BRCA1 and 2 is not the standard of care for risk reduction. But there are ongoing clinical trials of salpingectomy with delayed oophorectomy and that means people get their tubes removed, but they are planning to go back to take out the ovaries.

And I think most programs, including where I work, we do have these clinical trials open and many doctors are willing to offer just removal of the fallopian tubes for a person who is not ready to take out their ovaries. But for someone who's really ready to have standard of care management, who's of the

appropriate age, we really should still be recommending removal of the tubes and ovaries because there still is some concern that there may be risk for developing ovarian cancer with just removal of the tubes. We are all very hopeful that the ongoing clinical trials are going to prove that this is safe enough, but the data just are not there yet. And finally, we also know that for women who haven't gone through menopause yet, taking out the ovaries does reduce the risk of breast cancer. And so if we just take out the fallopian tubes, we may not be giving people that potential decreased risk for breast cancer.

And finally, I just want to end with some kind of general thoughts about cancer genetics and how we can do better. So we know that about 1% of people in this country have a cancer associated mutation, so that might be BRCA, especially among Ashkenazi Jewish patients, that might be Lynch syndrome or other syndromes that cause cancer. And unfortunately, the majority of people who have these mutations have no idea. And this is a tremendous problem because if they don't know they have BRCA1 or 2, they cannot benefit from potentially lifesaving screening and risk reducing surgery. If we did a comprehensive personal family history collection on people on the street or people in the Zoom or really anyone presenting to their regular doctor, actually a quarter of people meet criteria for genetic testing. And if we test those people, five to 10% will carry a genetic mutation.

But in the real world, we're not identifying these patients and less than 5% of individuals are identified and have the opportunity to undergo genetic counseling and testing. One of the things that my group is working on are pilots with technology. So we're using sort of iPhone risk assessment apps in the waiting room for mammograms or for senior general doctor to try to find out who's at risk so we can identify people and offer them genetic counseling and testing. And I think just in general, there needs to be more discussion about genetic counseling and discussion about cancer risks. So we can start to find all of these individuals who are affected and not aware. Because really ideally if we can find all people who are at risk, identify all of the BRCA1 mutation carriers, we can get people into programs for cancer prevention and care coordination so they can get all of the screening they need, breast screening, ovarian screening, pancreatic and more.

And that's really how we can save lives and really use genetic information to save lives. And so I'll just end my last slide. This is something I'm very passionate about. I'm working a lot on my center to make a program for cancer genetic testing and also for sort of once people have mutation, setting them up for care coordination and getting all of their screening tests. And this is my email here. Anyone is welcome to contact me if you have any questions about anything we've just talked about. Thanks so much for having me and I look forward to questions and I'm really excited to hear Haley Moss, who again is a good friend, former colleague, we trained together.

Dr. Haley Moss:

Thanks, Melissa, for that excellent presentation and I see that there's a lot of questions in the chat, but I think we're going to defer that until a little bit later on in the presentation. So my name is Haley Moss. I am a gynecologic oncologist at Duke University and also in the VA health system. I'm going to talk first as myself as Haley, a patient with a BRCA1 mutation and talk a little bit about my story and then I'll introduce you to my dear friend and colleague, Dr. Gerber. So where does my story begin? So my story begins where probably at very young age, my mom had breast cancer when I was young. She was diagnosed with breast cancer when she was 31 years old and I was very young and I still remember it to this day. She at some point had a testing at Mount Sinai when people were still just starting BRCA1 and BRCA2 testing.

She found out about it years after she knew about her breast cancer, went and got tested, didn't tell me until I was probably, gosh, 20 or 21 years old. At that point, I was a medical student at the University of Pennsylvania. There's an excellent program for BRCA1 and BRCA2 carriers there with us. Susan

Domchek, as many of you might know, I had genetic testing and I found out at around 22 that I had a BRCA1 mutation.

At that point, I started screening for breast cancer around 25. I left Penn and started going to NYU for my residency, and that's where I actually met Dr. Frey. She was one of my fellows in GYN oncology and I started doing the screening program at Sloan Kettering at that time. I was getting mammograms and MRIs every six months. I hated it. Every time I went, personally, I found it very traumatizing going every six months. Not all women and patients feel that way, but for me it was not the right thing. And so I decided to have a double mastectomy when I was 30. So I was a third year resident and OB G N at the time.

Just around that time, I was very much not ready to have children. It was not even on my radar. I was still a resident working a bajillion hours a week and I was about to start my fellowship in gynecologic oncology and I just was not interested in having children, but I felt like there was technology that I could pursue in order to prevent my kids from getting a BRCA1 mutation. And so I did IVF at NYU, that's a whole other saga, but it ended up being a whole long, very expensive journey where I had to do three IVF rounds in order to get some BRCA1 negative embryos, which I then froze because I was not ready to transfer an embryo at the time. Then I subsequently went down to Durham, North Carolina to do my fellowship and GYN oncology to care for women with ovarian cancer, but also folks that have a hereditary predisposition to gynecologic malignancies.

I was doing ovarian cancer screening and we're going to talk about that a lot. I was doing ovarian cancer screening, getting ultrasounds every six months, getting CA125s every six months. Even though I knew the science and I knew the data and Dr. Frey discussed that beautifully, there is no screening for ovarian cancer. It was something that I was doing because it made me feel like I was doing something and I explained this to my patients. So I'm switching to me as a doctor. When I talk to young patients with a BRCA1 mutation or BRCA2 mutation or any of the other mutations that Dr. Frey discussed, I tell them that there is no evidence that ultrasounds and CA125s detect ovarian cancer early and reduce your risk of mortality from ovarian cancer. That being said, I did it every six months because it made me feel I just wanted to look at my ovaries.

Anyway, I eventually had my daughter, was getting a screening ultrasound that showed concerning cyst on my ovary. Because I'm a GY oncologist, I was in the operating room within 48 hours and it was a benign ovarian cyst. So that just goes to show you the concern about doing ultrasounds because they're not really all that accurate and picking up ovarian cancer. Anyway, I subsequently had another child, my child, I have a three-year-old and a two-year-old, and just this past January I had a hysterectomy, and we'll talk about that. And I had my other ovary removed because I had my other ovary removed during that scare. And I also had my fallopian tubes removed at that time. So we'll also talk about the decision about removing fallopian tubes. I started hormone replacement therapy immediately, meaning I woke up from surgery and I already had an estrogen patch on my stomach and I'm happy to discuss that with you and my decisions and my thought process about hormone replacement therapy and BRCA1 and 2 carriers.

And here I am today with status post to double mastectomy removed my uterus, cervix, tubes and ovaries. I'm on estrogen. I have two children that do not have a BRCA1 mutation and that is me. I operate on women patients with BRCA1 and BRCA2 mutations probably every week. And it's a true passion of mine. This is a really important topic for me both professionally and personally. And thank you for inviting me to speak today. So now I will have you speak to Dr. Gerber, who is also a BRCA1 carrier and GY oncologist, but she is a very different story than my own.

Dr. Deanna Gerber:

Yes, thank you, Haley. That was very informative. Dr. Moss and my story is almost opposite of each other. So I am half Ashkenazi Jewish, half Sephardic Jewish. My mother's side of the family is Syrian. My father's side is Holocaust survivors, Eastern European. And so I have no family history of any breast or gynecologic cancer. And as early on in my career and in my medical training, I did wonder as an Ashkenazi Jew should I possibly be getting a BRCA testing. And I actually tried to get genetic testing many times. I tried to talk to see if my insurance would cover it, but because of my negative family history, I don't have any family history of any cancer, I was rejected. And so I never had any genetic testing. Cut to during COVID, I was 35, I had felt a breast mass and I went for my first mammogram because I felt something.

But at age 35, mammograms are not yet recommended routinely. They found a benign breast finding, but said come back in six months for just follow up. Seven months later, I let it linger a little bit longer. I went back and they found something completely separate that they were at the time of my mammogram, they were pretty sure it was breast cancer. And so using all my connections at NYU with all the friends I've made throughout my training there and throughout the years working there, I had a biopsy within 24 hours and I had my biopsy results within 72 hours. And that did show that I did have a triple negative breast cancer diagnosed at age 36. And so once that diagnosis was confirmed, it really threw me for a loop as I'm sure a lot of women on this webinar can recall the day finding that information. It's a really traumatizing moment and you'll really never forget that feeling and those words, someone telling you have cancer.

And so what ensued after that was that very day, because of my knowledge as a GY oncologist, I knew a 36-year-old with triple negative breast cancer definitely needs BRCA testing that's very concerning for a BRCA1 mutation. That same day I had an MRI, that same day I had my genetic testing. And after that I had 20 weeks of chemotherapy followed by double mastectomy, followed by delayed reconstruction. And at the time of my reconstruction, I was 37 years old at the time, I had my risk reducing cell salpingectomy for the BRCA1 mutation. So I had just my ovaries and my fallopian tubes. I still have my uterus in place and that is my story. I wish that many, many years ago when the thought of getting genetic testing crept into my mind that I had known to push for it or advocate for myself.

And that's something that we're definitely going to be speaking about tonight because there would've been a chance that I could have very likely prevented my cancer. And like Dr. Moss, like Haley, I am also on hormone replacement therapy, which also was a big conversation that I had with my oncologist. It was not something that she was enthusiastic about me going along with. But as a gynecologist and knowing the risks of menopause, I was very firm in my advocating for myself about being on hormone replacement. So I guess now we can open up the conversation and answer your questions and we can all discuss our differing stories and our different passions and how we counsel the women that come into our office.

Elana Silber:

Going to be a little challenging to see who wants to take what, but we'll see who's the most aggressive and who can get started. But we did get questions before, and now we'll start with the ones that we saw in the chat. So the first question that came in was for those with a mutation, do you recommend freezing eggs before the age of 30? That means assuming they know before the age of 30 that they're BRCA positive or another mutation. So we could start with Dr. Frey, I guess because it's been-

Dr. Melissa Frey:

Sure. I think I would start by saying there are many reasons why a woman would choose to freeze her eggs, and I think independent of a mutation, many women do it just because of thoughts on fertility and

timing and where they are in life. There is the technology available to, as Dr. Moss mentioned, sort of undergo IVF and then evaluate the embryos that one makes and only reimplant those that don't have BRCA. So really selecting for a baby that doesn't have BRCA, but I don't think that any physician should tell someone that's what they should do. I think it's a very personal question. I mean, obviously no one with BRCA would be here if their parents had done that. So I know that that's something that Haley has talked about and it's very complex.

And so I don't think it's our job to tell people to do that or not. I think it's our job to let people know it's available and then really leave it up to people. I also think BRCA today is very different than what it's going to look like in 20 years from now when these embryos reach adulthood. And so I think right now we're able to help people live normal lives just with a lot of medical interventions. And so you can only imagine that's going to be better two decades from now. I think if someone is certain they'd want to do egg freezing, then often doing it at younger ages is better just because the egg quality is better. And so if someone's going to pay for that and put their body through that, I think it always makes sense to do it younger if possible. But again, I think it's not a definite recommendation. This is something that all people with BRCA should do.

Dr. Haley Moss:

Yeah, I mean, it is a huge privilege that I was able to do it. It is incredibly, incredibly costly. Insurance does not pay for it. At the time, I was able to get money from Livestrong to pay for my very expensive medications to do IVF, which they are no longer offering to people who don't have a cancer diagnosis. But at the time, I don't know, maybe someone didn't read my application but I was very clear that I didn't have cancer, that I had a mutation. But now, and I don't know if Dede and Melissa have had a similar experiences, but now when I fill out the Livestrong paper work because I still try to do it for my patients, they get denied. And so it is a very costly endeavor to do IVF and embryo testing. And so I say that with acknowledging my privilege for being able to afford that and go through that. It's definitely not available to everyone. And yeah, the decision to do is a personal decision outside of having a BRCA mutation, kind of what Dr. Frey was just saying.

Elana Silber:

Okay, thanks. Can you please say more about whether BRCA1 women should have a pancreatic MRI and whether it is covered by insurance?

Dr. Melissa Frey:

I can take this on if you want, but I also want to give Haley and Dede a chance to talk. I think pancreatic cancer screening is one of the currently most controversial topics for BRCA1 and 2. And so as I said, for BRCA1, the risk is probably about 5% that someone will get pancreatic cancer. For BRCA2, that risk probably approaches 10%. The way the current NCCN guidelines are written is you have to have both a mutation and a family history of pancreatic cancer. But there are other guidelines more in the gastroenterology world that do allow us to offer pancreatic cancer screening to anyone with a BRCA1 or 2 mutation even without a family history. And I think many people would say, why do we have to wait for someone to get this to start a screening?

Which although there's not a lot of data, we do have some sort of emerging evidence that pancreatic cancer screening, which is MRI, and endoscopic ultrasound. So one year you would get an MRI of the pancreas, the next year you'd actually have to do an endoscopy and then they ultrasound the pancreas and go back and forth. So there is some evidence that if we do that, you can catch pancreatic cancer early when it is more likely to get surgically resected and people are more likely to have what appears to

be longer survival. Again, this is all very new, but I do think it's something that people should at least be aware of and whether or not insurance covers it, I think it depends. I am getting it covered for some people and there certainly are patient advocacy groups that are beginning to talk about this and fight for this. And I'm hopeful that the studies that are going on will push things forward in this arena. But I would say it's still an area of debate and controversy.

Dr. Haley Moss:

Yeah, I haven't had trouble getting insurance coverage for it since the American Gastroenterological, it's quite a word, society or has said that for any patients with a BRCA1, 2, PALB, some other mutations that it's warranted. I will say that we use the NCCN as like our bible for how to manage patients with germline mutations. And as of right now, yeah, it says if you have one of these mutations and you have a family history, Dede's a perfect example of a lot of patients don't have a family history of any cancer. We say maybe up to like 30% of patients have no family history of cancer for whatever reason.

Maybe everyone died of breast cancer or ovarian cancer, unfortunately, in 40. And so nobody could get pancreatic cancer. And I've heard, and I don't know if Melissa has heard that, I've heard that they're actually thinking of changing the NCCN guidelines in the next rendition for hereditary cancer syndromes to allow pancreatic cancer screening, but it's not official yet. So if you read the guidelines as of today, it'll say that only if you have a family history. But again, in the gastroenterology world, they say it's totally legit, they recommend it, and I haven't had any trouble getting insurance to cover it.

Elana Silber:

Okay. We're going to shift it a little bit. Somebody is asking about birth control pills. What's the connection between that in reducing cancer risk?

Dr. Haley Moss:

Dede, take that one on.

Dr. Deanna Gerber:

I'll take it.

Dr. Haley Moss:

Yeah.

Dr. Deanna Gerber:

Sure. So birth control pills is one of the few studied known interventions that we have in women with the BRCA1, 2, mutation that actually has been shown to decrease the risk of developing ovarian cancer. In general, when you think about risks for ovarian cancer, you think about anything that increases your number of ovulations. And so birth control pills shuts down ovulation decreases ovulation so that mutations can't occur. It's a little bit more nuanced than that, but essentially by shutting down ovulation, you can decrease your risk of birth control pills. And so that's something that I offer to all of my patients who don't have a reason why they can't be getting birth control pills with a BRCA1 mutation or BRCA2.

Elana Silber:

Okay. And can you start hormone replacement at any time? So for example, if someone had her ovaries and fallopian tubes removed a year and a half ago, is it too late to start?

Dr. Deanna Gerber:

If you don't have a prior history of cancer, then we as GYN oncologists, we recommend starting hormone replacement therapy as soon as possible. We know that it's most effective if you're starting it essentially right away, but really within six months is what the data shows, not just in BRCA mutation carriers, but in all women who are having hormone replacement therapy. So we try to start it right away, but if you don't have any reason to not be getting hormone replacement, I would still consider starting it. And usually we start it based on the symptoms. So most people come to us and say, "These hot flashes, I can't handle them anymore. Start me on something." And so we'll start them whenever.

Elana Silber:

Okay. Another shift, actually this question came in before. At what age do you recommend or is it recommended for genetic testing for children of BRCA carriers?

Dr. Haley Moss:

I mean, in my opinion, I don't think that you should do testing if there's no intervention. So people ask me all the time, "I have an 11-year-old, should I get her tested?" I mean, for me, I'm talking just my personal experience. It's heady to think of yourself as a mutation carrier. It's like why does an 18-year-old have to live with that if there's no intervention that's going to be had at that age? And so generally what I tell my patients is that between 20 and 25, closer to 25 is totally appropriate.

Dr. Deanna Gerber:

I think the current guidelines say that you should start around 25, but of course it's a conversation that is individualized and mutation carriers should have with their families.

Dr. Haley Moss:

I do just want to go back to the question about starting hormone replacement therapy because I get a lot of patients who are BRCA1 carriers, they're in their 30, and they've had their tubes and ovaries out by another provider and then are seeing me for a second opinion about hormone replacement therapy. I will generally start hormone replacement therapy. Ideally, you should start hormone replacement therapy like the day you had your ovaries removed. But a lot of GYN oncologists feel very uncomfortable with giving hormone replacement therapy. That is something Melissa and Dede and I are hoping to change, but a lot of GYN oncologists do not prescribe it. And so I see patients and they've been three years menopausal and they're like only 34 years old or 37 years old, and I feel comfortable starting hormone replacement therapy. They say generally ideally five years, like 10 years is a stretch.

I don't really feel comfortable doing after five years because there is some risk of starting hormone replacement therapy so late after already going into menopause, but that's generally when I stop. And I also saw something in the chat about stopping hormone replacement therapy. That's incredibly controversial. You'll hear some doctors say, "You should stop hormone replacement therapy between 50 and 55 because that's when the average woman will go into menopause at 53 in the United States at least." There's pretty good data that it's totally safe to extend hormonal replacement therapy to 60, 65 as long as the patient's counseled is on a dose of estrogen that is low enough to prevent any symptoms. And so it's a conversation that a patient has with a provider. There's no like up your 55, let's take off your estrogen patch. It's a little bit more nuanced than that.

Elana Silber:

Someone's asking, is there a thought to remove the uterus when taking out ovaries for BRCA2?

Dr. Deanna Gerber:

Let me take this one. So as Dr. Frey mentioned earlier, the data on hysterectomy or removal of the uterus for any BRCAA mutation carrier, the data's not so clear. It's not that it's controversial, it's just we don't have enough data to support doing it or not. And so the current guidelines, which Dr. Moss mentioned, the NCCN guidelines, we reference them a lot, say that it's reasonable to offer hysterectomy at the time of removal of the ovaries and fallopian tubes for BRCA1 mutation carriers. And that's because the few studies that have shown that there may be a link between BRCA mutations and uterine cancer are in BRCA1 mutation carriers. And so currently for BRCA2, there's no recommendation for hysterectomy because of risk of uterine cancer with women with BRCA2. However, in women with a history of breast cancer, hysterectomy can often reduce the risk of developing side effects of some of the common breast cancer medications such as tamoxifen. And so a hysterectomy can also be used for that risk, not because of the mutation.

Dr. Melissa Frey:

And I would just add one other piece to it. If someone has a uterus in place and wants to be on hormone replacement therapy, we give them estrogen and estrogen does sort of everything that we want hormones to do. It's good for all the quality of life measures. It's good for your bones. We hope, we haven't proven yet, but we think it's probably good for your brain and for your heart. But estrogen also tells your uterus to grow and get ready for a baby, or the lining gets thicker and then it's the progesterone that thins your lining every month. That's sort of what tells the uterus. There's no pregnancy. If we just give a woman estrogen, it can actually cause uterine cancer. So we have to give progesterone two to protect the uterus. Actually, progesterone is known to increase the risk for breast cancer. And so you're doing all of these things to prevent breast cancer.

And so it's also acceptable for a person to say, "I don't want my uterus in because I want my hormone therapy to be just estrogen and not have to take progesterone, which can increase the risk of breast cancer." And that is a totally acceptable reason to have a hysterectomy. I think that's another reason why we often offer it to people. The other misnomer is people think just taking out their tubes and ovaries is a small surgery and taking out the uterus is going to mean days in the hospital and a much longer recovery. And I think for most people the recovery is quite similar. It should be a same day procedure where someone is in their own home that night and walking and walking stairs and moving that same day.

Elana Silber:

I mean, I often hear people say, "I just want to get everything out. Just take everything out. Just take it all out." So I think that's a lot of people are considering what they could do once we're already doing surgery.

Dr. Haley Moss:

But I'll say that I don't routinely remove the uterus for a BRCA2 carrier who's not getting hormone replacement therapy. And so when a patient, let's say a 65-year-old patient comes to me, she has a BRCA2 mutation, I'm not going to start her on hormonal replacement therapy because she's already been in menopause for the past 15 years and she tells me, "I just want to take everything out. I'm done. I don't need my uterus." I counsel that there's no indication for her to have a hysterectomy because

she's not getting hormone replacement therapy, so she doesn't have to worry about taking the estrogen causing uterine cancer. BRCA2 carriers don't have an increased risk of uterine cancer.

And yes, Melissa said it's not that much bigger of a surgery, but there really is no indication for a hysterectomy for that patient population. Will I do a hysterectomy sometimes when there's no indication? Yeah, it's like having a conversation with a patient about the risks of an additional hour and a half being in the operating room, but there really is no indication for just taking everything out if you're a BRCA2 carrier and you're postmenopausal, I don't know with Dede and Melissa do in practice, but for those patients, I don't generally just remove organs because I'm in there.

Dr. Deanna Gerber:

Same. No, I agree with you. We're surgeons by trade and I love doing surgery, but less is more. And so I'm never counseling or coercing anyone to have more surgery than their guidelines and their desires currently indicate.

Dr. Melissa Frey:

And one other thing I would add to this that I apologize for not mentioning before, unfortunately, a lot of people get their BRCA diagnosis in the setting of having a breast cancer diagnosis. So that often means that someone's also dealing with chemo or radiation or maybe their tubes and ovaries are getting removed with their breasts. And so I think if a person has a lot of other things going on, the last thing they need is an additional surgery that's elective because the last thing we would want would be to have any complication or any issues with healing that could then prevent someone from getting to their chemo or their radiation. So I think for people who have a current active cancer, sometimes less is more in those patients especially. I wouldn't want to do something that is unnecessary.

Dr. Haley Moss:

I have had patients who don't get a hysterectomy get an IUD placed. The data about IUD and increased risk of breast cancer, it's all retrospective and it's not like the best data. Some papers will say that there is a signal that even if you have an IUD, it does increase your risk of breast cancer. Some say the opposite. The verdict still out about the safety of using a Mirena IUD for uterine cancer protection in a patient with estrogen.

Dr. Deanna Gerber:

I can speak from personal experience. I was not ready to have it. I'm very well-versed in the data, but I was not ready to get rid of my womb, my uterus at the age of 37. And so I elected to have hormone replacement therapy with progesterone. And so I have an IUD. I think one way to sum up everything here is that in women with a history of breast cancer, there's not a lot of data, good perspective, strong trials on the use of hormone replacement therapy in any capacity. And there should be because there's obvious risks to hormone replacement in women with history of a hormone positive breast cancers. But there needs to be more studies that look into this because as people can probably who've gone through it can tell you menopause, it's tough. And if you don't need to be going through it, then we want to do everything we can to alleviate that for you.

Elana Silber:

We talked a lot about trial studies and people want to know where can we find more information about participating in trials and studies regarding the salpingectomy with delayed oophorectomy. Where can you get that information?

Dr. Haley Moss:

The FORCE website, Facing Our Risk for Cancer Empowered, I believe. I looked at it a couple of days ago actually for something unrelated, but there's a section about there I think for studies for BRCA carriers to participate in. I know my institution, we have one of the trials open at Duke.

Dr. Melissa Frey:

Also, a website, it's a little bit harder to navigate, but it's called clinicaltrials.gov, and you can just type in like BRCA, it might give you a lot. But if you want to know anything that's going on for BRCA, that's a good place to look. And really probably if you have a gynecologic oncologist asking them because they should be aware if it's open at their site and if it's not, maybe know some other sites where it's open.

Dr. Haley Moss:

And the way those studies are done, they're not randomized. They don't force any patient to say, "You have to have your tubes removed." And then these patients get their tubes and ovaries. The patient ultimately decides what arm of the study they want to participate in.

Elana Silber:

And are there many of those going on now in the country? Are there many opportunities for that?

Dr. Haley Moss:

The SOROCk trial. I think WISP and TUBA have already finished. Am I correct with that? I'd have to look. I thought they finished recruiting patients.

Dr. Melissa Frey:

Yeah, I think there's one major one going on, but I think there is for some doctors, the opportunity to remove just the tubes outside of a clinical trial setting. Although this is, again, varies by provider, but I think it's something worth bringing up with your provider even if there is no study open.

Dr. Haley Moss:

First of all, you should have this conversation with a GYN oncologist. I feel very strongly that this is not an appropriate conversation to have with someone who's not a cancer specialist. So I would see a gynecologist or a gynecologic oncologist who specialize in caring for patients with hereditary cancer syndromes. And if you decide that for whatever reason, after talking to your provider, you do not want your ovaries removed and you just want your fallopian tubes removed. I have seen patients have trouble getting it covered for insurance because it's not the recommendations. And so generally when I code for it, when I do this surgery, I say it's a sterilization procedure, the person's doing it because they no longer desire fertility. And that's an indication for having just your tubes removed. But if your doctor just remove your tubes and bills it as for a BRCA mutation, I have seen patients have trouble with that in the past.

Elana Silber:

Okay. And I think that's the biggest takeaway. I mean, you've answered a lot of questions. It's really important to speak with your healthcare professional. Again, these are guidelines. Tonight's a springboard for conversations that you should be having with a gynecologic oncologist. Sharsheret does have a genetic counselor on staff. It can also help review a lot of the statistics that we've had tonight

and about risk. And Sharsheret also has resources about clinical trials on our site. So really thank you Dr. Frey, Dr. Moss, Dr. Gerber, for sharing so personally and for educating us. You answered a lot of questions and feel like you've shared a lot of good information and people are armed to take next steps or things that they're considering, you've helped explain a lot of it. Just a reminder that in a few minutes, we'll be starting our special bonus breakout program for the Embrace community.

For those women who are facing metastatic breast cancer or advanced ovarian cancer, anyone who's facing advanced disease is invited to stay on for an intimate breakout session with tonight's presenters and Bonnie Beckoff, Sharsheret's director of support services. I'm also going to ask you to please take a moment to fill out the brief evaluation survey that is linked in the chat box now. These evaluations really do inform our future programming, so I thank you in advance. Take a minute and really fill that out. We learn a lot from you. And please stay connected with Sharsheret, we're on social media, Instagram, Facebook, LinkedIn. I think we're Sharsheret official on Instagram. There are a lot of other mini Sharsheret programs and we post about events like these program updates, share personal stories, and so we hope you'll stay in touch that way. Coming up next, we have our 2023 Summit, October 13th to 31st.

It's called Pink, Teal and You. It's bringing together thousands of people, men and women, virtually and in person all across the country. This is our marquee educational event. You can join again virtually. We have materials, we have digital resources on the site, however you choose to participate. The summit is really a source for the latest information on breast cancer, ovarian cancer, and the effects in the Jewish community and beyond. Also, want to thank our sponsors again for tonight's webinar. Gilead, ImmunoGen, Novocure and Eisai. And Sharsheret Summit Sponsors, Merck, GSK, Daiichi-Sankyo, Lilly, Seagen, Pfizer, AstraZeneca, and Natera. Really appreciate your support and please remember that Sharsheret really is here for you and your loved ones. We provide emotional support, genetic and mental health counseling and other programs designed to help you navigate through your cancer experience before, during, and after a diagnosis.

Everything we do at Sharsheret is free, completely private, one-on-one, easily accessible. Our number is 866-474-2774. You can always also go on our website sharsheret.org. Email us directly at clinicalstaff@sharsheret.org. Our social workers and our genetic counselor are available and really eager to speak to each and every one of you. You're our priority. You're the only person in the room when you reach out to us, so please don't hesitate to reach out. And thank you for coming on this evening and stay well. And for those who are celebrating, wish you a happy and healthy new year and wish everyone good health.