It's a Family Issue: Hereditary Cancer: A Contra Costa County Community Event

Genetics Panel Webinar Transcript

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Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

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Sandy:

Welcome to this virtual hereditary cancer seminar and panel discussion. We are so happy to have so many people joining us tonight. Through meaningful collaboration and a sense of purpose, the Jewish communities in Contra Costa and Pleasanton have come together with Sharsheret, the UCSF Health Center for BRCA Research and John Muir Health genetic counseling department, to create what we hope will be an educational seminar and informative panel discussion on BRCA for men and women.

We thank the organizers and co-sponsors, Anshei Isaiah, Beth Chaim Congregation, B'nai Israel of Rossmoor, Chabad of Contra Costa, Congregation dot Emet, Congregation B'nai Shalom, Congregation B'nai Tikvah, Contra Costa JCC, Contra Costa Jewish Day School, Diablo Valley Hadassah, Interfaith Council of Contra Costa County, John Muir Health, National Council of Jewish Women, Sharsheret, Temple Isaiah, UCSF Center for BRCA Research and Women of Isaiah working together. May we continue to move from strength to strength. It is now my pleasure to introduce the moderator of the program, Aimee Sax, the California program coordinator for Sharsheret.

Aimee Sax:

Thank you so much, Sandy. And thank you so much to the amazing consortium of Contra Costa community partners for hosting this program. I have never worked with this many program sponsors before and community partners, and it has been amazing to get to know you all. And thank you in particular to the committee of dedicated volunteers, all of whom have been working since November of last year to bring Sharsheret to your community. And we have over 200 people registered tonight, so your work has not gone unnoticed. Thank you so much to all of you and to everyone here for joining us. So Sharsheret, for those of you who don't know is the National Jewish Breast and Ovarian Cancer Community. We are here for non-Jews as well. We are in all 50 states, so if you go away with one thing, please know that we are here for everybody.

We provide free, confidential and personalized support before, during and after diagnosis. So we're really here for everyone, whether they're just considering genetic testing, whether they've gotten genetic testing done or have an actual diagnosis, whether it's a genetic mutation or cancer diagnosis, whether they're a caregiver from near or far, or whether they're 10 years or more into survivorship, we're here for everyone. We have a team of social workers, a genetic counselor, and educational staff here to support you and your community in whatever ways we can with our programs outside resources and more. This evening we'll be discussing the latest information surrounding the relationship with the Jewish community and our risk for cancer, but we will also touch on the risk for the general public as well. We'll be discussing hereditary cancer, focusing on the BRCA1 and BRCA2 gene mutations which greatly increase the risk of breast cancer, ovarian cancer, prostate cancer, pancreatic cancer, male breast cancer and melanoma. And disproportionately impacts the Jewish community, especially people of Ashkenazi ancestry.

We'll also touch on other gene mutations associated with other cancers as well. So if you're comfortable for anyone who is still sharing their screen, please raise your hand if you've had a friend diagnosed with cancer, and you can keep it raised. Raise your hand if you have a family member who's been diagnosed with cancer and keep your hand raised. And now raise your hand if you yourself have been diagnosed with cancer. So you can see from the amount of hands raised that this is a conversation that every family and specifically every Jewish family should be having. So without further ado, our esteemed panel tonight includes Dr. Pamela Munster, who is a professor of medicine at the University of California, San Francisco. We're at the Helen Diller Family Comprehensive Cancer Center. She's the leader of Experimental Therapeutics Program, director of Early Phase Clinical Trials Unit and co-director of the UCSF Center for BRCA Research.

Aimee Sax:

Her lab explores new ways to detect and cure BRCA-related cancer. She also develops strategies to treat patients as an oncologist. She serves on local, national and international committees focused on developing new treatments. She's published articles, textbooks as a frequent lecturer. As a native of Switzerland, she leads breast cancer awareness campaigns across the globe. And she herself was diagnosed with BRCA2 mutation in 2012, and found that there was no easy place to coordinate her care. So she set out to create the UCSF Center for BRCA Research in partnership with Dr. Alan Ashworth, by transcending the doctor-patient perspective. She optimizes the personal patient-centered care that is a hallmark of UCSF Medical Center. She also authored Twisting Fate about her experience as an oncologist in cancer patient.

Josh Barnhart is an oncology genetic counselor at John Muir Health. He received his bachelor's in genetics and genomics from UC Davis and his master's degree in genetic counseling from Virginia Commonwealth University. He was born and raised in the Northern California area and is passionate about helping each individual patient learn about the complexities of their hereditary cancer risk, and providing them with support through their hereditary cancer journey. Raleigh Zwerin grew up in the Bay Area where she now lives with her husband and two teenage children. She taught first grade for many years and now runs a master's credentialing program for elementary teachers based out of Oakland. Tonight, she'll her personal story with us. So what's the format for this evening? First, we'll hear from our panelists and then we'll open it up for questions. And if you already sent in questions, thank you for those. I have those.

If you think of a question during our event, please feel free to write it into the chat. You can write it in publicly where it says everyone at the top, or you can click on my name or Sharsheret's name and ask the question privately just to me, and we will try to get through as many as we can, but because we had so many submitted beforehand, I'm sure that we will have some leftover, so just know that we will still try to answer everyone's questions after the event. And I'll be following up with an email in the next week or two with answers to the rest of your questions. So I'm going to keep this evening moving along. So without further ado, let's get started. So Raleigh, let's start with you, and if you can please tell us how you learned about BRCA mutations?

Raleigh Zwerin:

Hi, about my own personal mutation?

Aimee Sax:

Mm-hmm (affirmative).

Raleigh Zwerin:

Yeah. It was six years ago and I was walking out of synagogue on Rosh Hashanah with my son and my daughter and my husband, and that is when the genetic counselor called in the way as we were walking to the car, to tell me that I was BRCA1 positive. It was a mutation that I was not surprised that I had. It was because my sister had also just learned that she was BRCA1 positive, and it was the second test that she had taken. She took a test to find out 10 years, excuse me, five years earlier and she learned from that first test that she got ... She took the test originally because she went through a girlfriend, gave her the genetic test for free. It was a girlfriend who worked for a genetic testing company and that girlfriend gave her the test and she got the results of that test online. They were digital results, and she looked at the results and didn't really see anything unusual or alarming about what she noticed online. And we didn't even really know that that original test was testing for the BRCA mutation. And so it wasn't until

the actress, Angelina Jolie came out with her story. She's also BRCA1 positive, that my sister and I decided to go to our own doctors to ask if we should be tested.

Raleigh Zwerin:

Our maternal grandmother, my mom's mom died when my mom was just one year old of breast cancer. And we're both Ashkenazi Jews, and so when we asked our doctors, the doctors said, no, actually that we weren't candidates, that both of our parents were perfectly healthy and there was no need for us to be tested. So we didn't really think about it again. And it wasn't until my sister decided to get her dog tested for a DNA test. She had a Mutt and she wanted to see what kind of dog she had, that she kind of remembered the first genetic test that she had actually taken and she pulled those results up again online and looked at them. And at the very top of the page for the very first time, they were the same digital results that she had received but this time it said BRCA1 positive at the very top of the page written in red.

So, she got retested. That was her second test. And again, confirmed that she was positive. My brother was negative and we assumed that, of course, this mutation came from my mom because her own mother had died at such a young age of breast cancer. But this mutation didn't come from her, it came from my dad. And my dad is one of three brothers, his dad was one of three brothers. We didn't really realize that the mutation would have come from him or there was really any risk because all of the men in his family, some did die of cancer but they did it at an older age. So we were surprised by those results.

Aimee Sax:

Absolutely. It's such a riveting story and all the twists and turns, so we'll come back to you for a little bit more of it in a little bit. Dr. Munster, can you tell us a little bit about the general population risk for cancer?

Dr. Pamela Munster:

You mean not in someone with hereditary cancer?

Aimee Sax:

Exactly. Just the general population and if there's relationship between age and cancer risk.

Dr. Pamela Munster:

Yeah. And people please forgive me, I'm a professor and I quickly start lecturing so if it gets boring and I'm guilty, let me know. But I think the important part is, breast cancer is quite common. About one in eight women, at some point upon her life will be affected with breast cancer. Ovarian cancer on the other hand is not that common. What's different for someone with hereditary cancer is two-folds. One is women with BRCA mutation tend to have cancer a little bit earlier in life, and there's often more breast cancer in the family. What I find really important to know, and that's why I'm here and find it so important that people could remind that they could have a hereditary mutation, if Raleigh and I had known that we had a mutation, we probably would start screening much sooner.

So when I was diagnosed with breast cancer at 48, first of all, I didn't think I had enough breast that I could actually have cancer. And I was of course reminded that this is not the case. But the reality is there was no reason for me to believe that I would be at risk for breast cancer. My mutation comes from my father and he was a single child and his mother breast cancer, but she was older so this was not

considered in my mom's family. There's no breast cancer. So I think the take-home message is really if I had known I'd probably be more prepared, and I would have taken more precautions. And I think that's the difference. And then the hereditary mutation as we'll talk a little bit later, and I hope to hear from Josh, as well as associated with all the cancers that are more important to prevent.

Aimee Sax:

Yes, we will definitely be talking a lot about that tonight. So perfect segue, Josh. What is the risk for being a carrier of the BRCA gene mutation? And how does the risk for being a carrier change for a member of the Ashkenazi Jewish population?

Josh Barnhart:

Yeah, that's a really important question as well. So oftentimes the number, you can look up, it varies a little bit, but for individuals of just the general population, oftentimes that risk is core at around one in 300 to about one in 500. So it is still relatively rare, less than 1%, even for someone of the general population to have a specific genetic change or a positive result within those BRCA genes. However, for individuals who are of the Ashkenazi Jewish ancestry, individuals have a higher risk, is about one in 40 for those to have a specific genetic change within those BRCA genes. So it is something that greatly elevates. It's almost 10 times greater increased risk for those who are of Ashkenazi Jewish ancestry versus those who are of the general population.

Aimee Sax:

Absolutely. It's such a big difference. And why is that difference? Why is the Ashkenazi community at greater risk?

Josh Barnhart:

Yeah, that's a good question as well. So oftentimes that comes down to, for individuals who are of Ashkenazi Jewish ancestry, they have specifically a higher risk to getting three specific genetic changes within the BRCA genes. They're oftentimes called founder mutations. And one of founder mutation is, is essentially when you take a small group of individuals, and oftentimes that small group of individuals is oftentimes due to either religious isolation or geographic isolation. All what can happen is as they populate over generations, there were specific rare mutations that were within that initial small population, well, can grow that as these generations go on. These rare mutations can be seen in more often in this population.

So for individuals who are of Ashkenazi Jewish ancestry, well, most of them did come from initially what are called those founder individuals. Those founder individuals were a small group of population and so we assume that they interbred between them, and over time, these mutations that were relatively rare but within that small population became more common within that specific, like I said, Ashkenazi Jewish ancestry, which leads to that higher risk of those, of just the general population. So that's where-

Aimee Sax:

Great. [crosstalk 00:14:49] in the family.

Josh Barnhart:

Yeah. So within the family, which is why that higher risk is [crosstalk 00:14:55] to no other.

Aimee Sax:

Right. And Josh-

Dr. Pamela Munster:

Maybe I can add something here. I think that's probably an important point with, because the BRCA mutation or even ATM check don't actually impair fertility or manifest that early, you actually don't know mostly that your spouse may carry this mutation. Because in another diseases where diseases manifest at a younger age and you would know that the family carries the gene, this will probably be eliminated, but this is what leads to the accumulation of these gene families.

Aimee Sax:

That's a great point. And like you both already shared in your stories, if it's coming from the father's side and it's a small family, then you're even less likely to see that. Josh, what do we know about risk levels in the Sephardic community?

Josh Barnhart:

That's also a good question. So we know that individuals who are of the Sephardic Jewish population as well also can have genetic changes, not only within these BRCA genes that we keep mentioning, but with other genes as well. We know that oftentimes they'll because they don't come from that necessarily that same population that that risk is still there and so we still want to make sure that individuals who are of a Sephardic Jewish population still can get testing, but oftentimes the family history is more of an indicator to say, does it seem more likely or less likely? So it is something that, that population is still at risk. It doesn't mean that they're not, but it is something that all individuals or of Ashkenazi Jewish is typically still higher than those of the Sephardic Jewish population.

But still something that absolutely be aware of given the context of the family history, and something that is still there as we do know individuals who are of the Sephardic Jewish population, some of those individuals still have some of those founder mutations that are found within the Ashkenazi Jewish population. So it is still something that'd be very important to be, and keeping your eye on, asking questions, family history, getting to know about your family a little bit in terms of at least breast cancer or ovarian cancer risk, and these other cancers that we're going to go over as well later on, but definitely something important to know that risk isn't as high, like I said, the Ashkenazi Jewish population, but something that still exists.

Aimee Sax:

Right, so Dr. Munster, can you speak a little bit about what are these genes? What does the BRCA gene do and what happens when they don't work correctly when they have a mutation?

Dr. Pamela Munster:

So BRCA1 and BRCA2 and populated in different chromosomes. If I can take you back to biology, one is on 17, the other one is on 13. Every one of you has two BRCA genes, two BRCA2, two BRCA1. Now one of them can get abnormal, and there can be many, many spots. So there's about six or 7,000 abnormal BRCA mutations now. So there's many different versions of ... The Jewish community only have three that are very common actually. But if you don't have one of the three common, you could still have had any of the others. So it's very easy to mutate this gene, not every mutation causes cancer. And I think

that's where some of the question comes from is, why does Ashkenazi Jewish members not only have a frequent gene but also frequently they have cancer?

Dr. Pamela Munster:

It does seem to appear that if you have a mutation, it does matter where the gene expresses itself. We see BRCA mutation families and they have very few cancers. We see BRCA mutation families that everyone who has two mutation also seems to have cancer. So I think the mutation ... BRCA mutation does not cause cancer, it puts you at risk for cancer. So having the mutation is not a test that tells you, you have cancer. It tells you that you're at risk for cancer. So if you go for a genetic testing and you come back with a positive BRCA mutation does not mean you have cancers. A lot of time people under this misconception to get a test, and that test tells us whether you have cancer, you have a risk to get cancer. And then we'd like you to screen.

So the important part is BRCA mutation. Probably the highest risk associated with BRCA mutation is breast cancer. Second is ovarian cancer, but then pancreatic cancer for both men and women, and then also prostate cancer. Melanoma is a little bit less clear, because melanoma is quite common in fair people. Because melanoma is actually quite common as BRCA mutation is common, it's not so clear whether you have a true link between melanoma and BRCA mutation. And I think Josh, you probably would agree because skin screening is such an important part because it's such a preventable cancer. We tried to sort of like in our recommendation for hereditary screening, we like to slip in the skin cancer screening because it's easy and it's very effective. But then BRCA mutation can cause other cancers or it can be associated with other cancers. So it's often a cancer enabler. So we often see cholangitis which is associate with gallbladder. Sometimes bladder, sometimes colon is smattering of other cancers. We just have not quite as good an understanding how clearly they are linked.

Aimee Sax:

Absolutely. Thank you. And can you speak a little bit, Dr. Munster about how BRCA gene mutations run in families, and how often do they come through the male side of the family?

Dr. Pamela Munster:

Well, the gene is passed on since you have two of them, and usually brown is mutated. Every offspring has a 50, 50% chance of carrying the gene. So you can get the mutation from your father like me or you can get it from your mother like others. It can come from either sides, and I think it's important to look at your father's side as well. I think in the last years hereditary component from the fathers has often been overlooked. Of course, not like someone as in tune with this like Josh, but a lot of doctors often just focused on the mother's side. They're not as much as [inaudible 00:21:12]. And if you just take one look around, it seems like the women are much more into the health care than men, if you just look at how many women are on the call compared to how many men, and I really like to give a shout out to all the men who call in, it's really important that we have the awareness from the male family members.

Aimee Sax:

Absolutely. I second that. Raleigh, can you tell us a little bit about how the conversation has gone since you and your sister tested positive? What was the conversation like with the rest of the members of your family?

Raleigh Zwerin:

My sister and I talk multiple times a day on an average day, embarrassingly sometimes about absolutely nothing at all. We just sit there in silence, but our conversations very early on when we first learned that we were BRCA positive were of course all centered around this mutation, what it meant. We tried very quickly to get educated and learn about this mutation. And as Josh said, learned that as Ashkenazi Jews, our risk was one in 40. Doctors told us that we had a lifetime risk of more than 80% chance of getting breast cancer and over a lifetime risk of 40% of getting ovarian cancer. They told us that there were no really good screening options for ovarian cancer to detect it early. And that the screenings for breast cancer were better, but that it was much better to go in for surgery as somebody who was healthy versus somebody who wasn't well.

So for us, the choice was just really clear. Each decision and conversation that we had was really multilayered, do we have breast reconstruction? Our implants, if we decide to get them, do they go under the muscle or over the muscle? And then our conversations really continued on and continue to this day about making sure that we are being monitored. We both have two kids and we talk about that in the conversation, when should they be tested? We were told that my daughter shouldn't be tested until she's in her mid-twenties, and our son's a little bit later than that. The conversations really were about how we feel about, we felt very, I should say blessed in many ways to sort of learn about this mutation when we were both still healthy, because we know that is really not the case for so many people, but more often than not learn about this mutation when they are sick themselves. So often we just talk about how fortunate we feel that we learned when we had preventative options.

Aimee Sax:

That's such a lovely way to look at it. I love that. Thank you. So Josh, can you tell everyone a little bit about how genetic testing is performed?

Josh Barnhart:

Yeah. Good question. So in terms of how it's performed, I mean, it can be done oftentimes two different ways nowadays, so we can either do a blood draw or a saliva test. So those are the distinction in terms of how we can go about getting your DNA in terms of actually doing the genetic testing. But genetic testing is done in a lot of different settings nowadays. So sometimes it's when individuals have this family history or they know someone within their family who has some genetic component, maybe it's in one of these BRCA genes, for example. And they come in and do genetic testing in order to say, okay, do I have this? And if I do, well, let's make sure I'm being more proactive about it and I can take these preventative steps that are needed to do. Sadly though for some individuals, they don't do genetic testing until they actually have a cancer diagnosis. And for those individuals it can be important, oftentimes that they have breast cancer, maybe for their surgical decision in terms of, do we recommend doing a double mastectomy versus maybe just doing what's called a lumpectomy, sometimes called breast conserving surgery.

So sometimes it comes down to individuals who have this family history, they want to know more about it and to contextualize, is there some genetic component for that? And for other individuals, sadly they're not able to go based off of that. It's because they actually have that cancer diagnosis to say, okay, well, now that this has happened and we know that there's this family history, well, let's make sure to see there is a genetic component. There's anything prophylactically that we'd recommend based off of that. But in terms of actual genetic testing itself, at this point it's currently two different options to see either the blood draw or we can do a saliva test as well.

Aimee Sax:

Thank you. And what age is best to undergo genetic testing?

Josh Barnhart:

That is a complicated question. Not as for sure. So it could be a couple of different things. I think for Raleigh's case, absolutely it is something for daughters, for women who have ... A mother maybe who has a BRCA mutation. It is something that sometimes we may suggest in their early twenties. And then because of the early twenties, we say that because for BRCA specifically we recommend starting breast MRI screening, so screening for breast cancer at the age of 25 for those who actually have, like I said, a genetic component within one of these BRCA agents. So oftentimes for females, we say oftentimes when they're younger twenties. For men, cancer screening is, we're most concerned about is for that prostate cancer. And that screening typically isn't recommended until the age of 40.

However, with that being said though, there are absolutely individuals who come in at 18 and 19, who still want to know, even though that they may not recommend anything until the age of 25. So it is something where it's very dependent on I think every individual's choice of when we may recommend doing it versus when we may not. It's just with the idea that we always say that for these adult onset cancers. So specifically for these BRCA genes, these are adult onset cancers. We don't recommend doing genetic testing and tell someone's at least the age of 18. And that's because for that age of 18, well, they can properly consent to doing genetic testing. They can fully understand, well, why am I doing this genetic testing? How is it going to be useful? What am I going to do based off of these results?

However, based off of that, you can start at 18. If you're someone who really wants to know right away. How are oftentimes? Like I said, for females who have some family history or they know, oftentimes we may say early twenties is a good time. However, at the same time, I always say every time is a great time for doing genetic testing. Ultimately, if you know you have a family history, it really doesn't matter whether you're seven years old, 18 years old, 85 years old, it's always good information for you. It's always good information for the family. So sure we might say there's a prime age because that's when we may start screening, but really what I would say is anytime is really a great time to learn about your genetic risk and to learn more information about yourself and more information that could really benefit family members as well.

Aimee Sax:

Knowledge is power. I love that. Dr. Munster, I think you wanted to say something about this as well.

Dr. Pamela Munster:

Yeah. Having BRCA mutation, and when my kids were young and I was first diagnosed with the BRCA mutation, of course, I just wanted to know whether they have it. And it's very tempting to test it. I have a lab, I could have just taken my daughter's DNA tested. And I thought, well, if I tested it then I know I would just keep this as a secret, and my friends would tell me that I can't keep the secrets on a good day so how would I keep this secret? But what I think would really feel very strongly about is that you let your kids find out when they're ready. And I think as parents and as family members, we put a lot of pressure on the kids to get tested, but I think there's probably better times and there's worst times, because we start screening at 25 but we see very, very few women at 25 with breast cancer.

Of course, they exist. But sometimes in the life of a 25 year old, there's college, there's decision-making, there's such an overwhelming onslaught of important and difficult decisions that maybe knowing about their BRCA mutation is probably not the right time. And you put them part of genetic counseling is that we can screen someone without them knowing whether they have the mutation. It is like, let people be

ready. There's one thing that's probably worse knowing, if you have a mutation you have a chance of passing it on. And so if you don't know and if you were a BRCA mutation carrier and your spouse is, and you have a child, this one in four children have a chance of having Fanconi's anemia.

Dr. Pamela Munster:

So these children have really a bad disorder with leukemia and often resulting in pregnancy loss. So if your children marry someone from another significant family history, likely a BRCA mutation would then probably be good to know before I do genetic prenatal testing. So there's the two important things. One is you should let the kids find out themselves. But as I said, if there's two families with really significant family history, you probably want to do prenatal testing.

Aimee Sax:

Absolutely. Thank you. Okay. We have lots and lots of questions. So I'm going to ask our panelists to try to keep it tight because even more questions keep coming in. And it's really exciting in knowing a lot we want to get to. So Josh, if people have been tested in the past, let's say five or more years ago, have the tests changed significantly? And what should people consider if they want to get tested again?

Josh Barnhart:

That's some good questions to say. Absolutely. Genetic testing does change actually on a pretty regular basis. So when we say genetic testing has changed, it's not that getting your DNA is any different or anything like that. It simply means that as time goes on, is that genetic is still a young field and we're continuing to learn of new genes that are associated with cancer. So I always give the example in clinic that oftentimes in 2005, we really only were testing for those BRCA genes, specifically, the ones we've talked most about today. However, as time has gone on we've continued to learn of new genes that are associated with breast cancer, with ovarian cancer, with colon cancer, with a lot of different types of cancer.

So oftentimes nowadays we're doing testing called multi-gene panel testing. And what that means is that we're oftentimes testing multiple different genes that are associated with a variety of different cancers to say, okay, we know these BRCA genes are the most common genes associated with a genetic cause for breast cancer, but there are actually other genes that are associated with a genetic cause for getting breast cancer, for getting ovarian cancer, for these other cancers as well. So I always say that if you had genetic testing five years ago, it's important to bring up whoever ordered that testing to say, okay, what were these genes that were looked for? Has there been any new genes that have recently found to say, okay, should we be testing for these other additional genes then?

And that's because what I tell people is you can always get a negative result and a negative result is oftentimes, it is the good news. That's what a lot of people hope for when they're doing genetic testing. But a negative result doesn't necessarily mean that there isn't some genetic component that could explain that family history. It always could be that simply, we just don't know what's going on genetically at this point and we could find something in the future. So my suggestion, like I said, if you did it done at five years ago, it is something that, just talking about who ordered that testing, what do we recommend doing anything additional? Have we learned of anything new at that time? So it's definitely always something to be considering of. As time goes on, we're only going to continue to learn more and more genes that are associated with these cancers as well.

Aimee Sax:

Thank you. That's so helpful. Dr. Munster, can you talk a little bit about for people who have a strong family history, but then test negative for the BRCA gene mutations? So Josh just mentioned there are other genetic mutations. Can you give a little bit of an overview of the most common gene mutations that can lead to these cancers?

Dr. Pamela Munster:

Yeah, there was two interesting publications just recently coming out looking at 60,000 women. It's like, what is the most common genes in breast cancer? And not surprising BRCA1 and BRCA2 rank very high. But then there's the ATM mutation and the CHEK2 mutation and probably two, which also are known to be pretty significantly associated with an increased risk of breast cancer. So if you quote women with BRCA1 or two mutation, anywhere between 60 to 80% risk of breast cancer over a lifetime, for CHEK2 in ATM, this is probably somewhere 20 to 40%. So we call them moderate cancer genes. But if you have a 40% risk for breast cancer over a lifetime, we still think this is fairly high that we start screening earlier than we would in a woman without significant risk.

And then there's PALB2, which is department and localizer for BRCA2, which is probably less common but associated with very significant increased risk for breast cancer. Some of us call this loving the BRCA's free, and I think these are the major mutation. TP53, which is Li-Fraumeni syndrome is also associated with very young breast cancer, but the mutation is quite rare so we don't see this. But overall there's about 5% of mutation that contribute to breast cancer. So it's actually having a breast cancer mutation, probably a little bit more common than we thought. We thought this is one in 200, but if you take all the mutations together, it's probably about one in 50 or more.

Aimee Sax:

Wow! And so Dr. Munster, when should people be considering genetic testing? If they have no family history, if they aren't currently basing a cancer diagnosis, does it make sense for them to get tested?

Dr. Pamela Munster:

So glad you asked me this. I know it is not everyone agrees with me. It's like, before you said knowledge is power, so I would have never qualified anywhere for any testing because I don't have enough family. So family history assessment is really good if you have a lot of family members, but what if you don't? What if you have your father has one brother and your mother has no siblings, how would you even assess your family history? What if your parents don't live long enough to assess whether you have a risk for breast cancer? My point is I would test any woman because I do not want to see another woman with a big tumor walking into my clinic that could have been prevented, but not everyone feels like we should have this much knowledge. So I think it's the question of the future. I would suggest however, if you want to find out about your BRCA status, don't do 23andMe

Aimee Sax:

I hear that. We're definitely going to talk a little bit about that, but since you brought it up, if you'd like to speak a little bit about what quality are the over the counter testing options. I know that some of them are medical grade, some of them might not be.

Dr. Pamela Munster:

So the 23andMe test is very good. If you are an Ashkenazi Jewish person and you have one of the three founder mutation and you have a BRCA mutation by 23andMe, it is real. Okay. If you're like me, I'm not of Ashkenazi Jewish heritage, the 23andMe does not test for my mutation, so they reported my breast cancer risk as normal. And my BRCA mutation was negative. Obviously that's not accurate. There's a disclaimer in 23andMe, they're not intentionally misleading. But it would give you an analogy, but what if you did a pregnancy test that only would turn positive if you're Jewish, how would this be an acceptable pregnancy test? So this is the problem between 23andMe. So the problem is they're really only testing for three mutation and for BRCA. Today, probably now about 6,000 mutations around.

Aimee Sax:

Yes. Well, thank you for that. So Dr. Munster, can you talk a little bit about what options do people have when they do test positive for a BRCA mutation?

Dr. Pamela Munster:

I think the most important part is when you learn that, that day you don't panic, because that doesn't mean that day that your cancer risk starts the next day, even though. I'm sure Raleigh, that's exactly how everyone feels, you learn about your mutation and immediately you think your cancer risk is right around the corner. Of course, if you have a cancer and then you learn that you're also BRCA mutation, then that has implication on the treatment. So it's important. But I think the reason why we built the BRCA Center for Research is for people to actually have someone to go talk to. And I think that's why our genetic counselors are so important. This is the time you sit down with Josh, and Josh walks you through what are the screenings? What are the recommendations? What are the next steps?

And then more important than anything, we do a lot of screening. But what happens if you had a mammogram in June and it was totally normal, and an MRI in December, but in February you find a lump, who do you call? What I see is so much, still a problem is people find something and they just don't have anyone to call. And then it takes two, three months until they organize the physicians visit and then it's gets forgotten. And then six months later, someone comes with a very large tumor that probably would've been much smaller six months from now. I think the important part is if you had a meeting with Josh and three months later you call him and say, "Oh my God, I have a lump." Josh is probably going to say you need to go see Dr. X. And if you call us we guide you, but if the important part is not to disregard new lumps and findings on your body.

Aimee Sax:

And can you tell us a little bit about increased surveillance and prophylactic measures?

Dr. Pamela Munster:

Yeah. Someone with BRCA1 or 2 mutation at 25, we start doing MRIs. And then at some point we add mammograms. This is a bit less certain. We start talking about ovarian cancer screening and prophylaxis by 35 or when women have completed their childbearing, is that this is not that easy to go into menopause at very young age, but there's an option of providing some hormone replacement therapy, which is actually quite safe even in BRCA mutation carriers. And then for men, we start doing prostate screening probably at 40. I personally feel very strongly about colonoscopies because colon cancers are very preventable. The tumor when it's diagnosed early as a polyp, I think it's important to do melanoma screening. And then as I said, more important than anything is if you have a finding, call someone. I just said [crosstalk 00:41:00]

Aimee Sax:

Absolutely. Thank you.

Dr. Pamela Munster:

Josh, did I forget anything?

Josh Barnhart:

The last thing I would just add is in terms of the pancreatic cancer screening is that, that is something that is relatively new in terms of us doing the pancreatic cancer screening as well, to simply say that. There is this elevated risk as well. So oftentimes for individuals who have BRCA1, BRCA2 genetic mutation and then also have a family history, well, we oftentimes talk about doing potential screening as well, which is something that was exciting because 10 years ago we weren't doing as much pancreatic cancer screening where something that's become much more prevalent in the last couple of years, especially. That's the last thing, but otherwise I think, no, absolutely. I appreciate that.

Dr. Pamela Munster:

[crosstalk 00:41:42] because this is actually quite controversial. And I feel quite strongly that we started screening, and right now the screening recommendation, only for people with BRCA2 mutation with family history, but I don't think there's enough evidence of BRCA1 is not a risk factor. So we started doing a study for BRCA mutation carriers over 50 to get MRIs on study. So I think I really like to get that data. There's a lot of unknowns in the pancreatic cancer screening.

Aimee Sax:

Absolutely. So Raleigh, can you please tell us what measures you have taken and tell us what that experience means to you?

Raleigh Zwerin:

My sister and I both decided to have bilateral mastectomies and we decided to have what's called a salpingo-oophorectomy to have our ovaries and fallopian tubes removed. We each had two surgeries. We staggered them so that we could be there to take care of each other and that our parents and families who are most of them local Bay Area. People were there to also take care of us. The decision was an easy one in many ways for us, just because it felt like the evidence was so overwhelming that there was a really big risk that we would get sick. And we decided that it was really important that we took these preventative measures, but I will say that decision was made far easier because we both had partners. We had already had our children and we were sort of closer in age to when we would naturally go into menopause. And also it was just made easier because we had this tremendous support from our families, from our partners, from our parents who all really agreed that this was the right decision for us to make.

Aimee Sax:

I love how you always have that positive spin to put on things and really focused on the gratitude and all of that, of the situation. And also highlighted that that's not easy for other people and that other people are going to make the choices that are right for them. I think that's something that I talk about all the time with our Sharsheret callers, because I speak to people who similarly have a sibling that's diagnosed and is making a different choice than theirs, and how that family dynamic can be very difficult. So I'm so

sorry you had to go through this, but I'm so glad that you had all of that support. And it sounds like your family really, really came together. That's beautiful. Thank you for sharing.

Aimee Sax:

So we've already kind of touched on different screening for different cancers so thank you for that. We've also talked a little bit about how much things have changed in the past few years. So we hope that that continues. We hear all the time, how could things be different for our children? So Dr. Munster, what new screening technologies are in the research pipeline, you talked a little bit about research you want to see, what work is being done on BRCA mutation prevention as well?

Dr. Pamela Munster:

The couple of things, I mean, is that the group in Philadelphia, they're working on a vaccine. Not ready for prime time yet, but hopefully getting there at some point. There's a lot of early diagnostics in terms of the circulating tumor cells, meaning a tiny piece of the tumor clots your blood and we can pick up by DNA for earlier tumor detection. That's incoming and actually quite exciting. In terms of breast imaging, there is new tumors. People are working on laser detection. There's quite of interesting studies looking at estrogen receptor signaling, there's PSMA PET for prostate cancer, there's hyperpolarized magnets for pancreatic cancers. It's actually a lot of work is going on.

Unfortunately nothing is quite ready for you go and do this tomorrow, but I think I also would like to put a plug in for those who know me or know that I always do that. There's a lot of evidence that life style choices probably are relevant for people with BRCA mutation, that includes a normal weight, that includes exercise for pancreatic cancer. Absolutely, smoking and alcohol are detrimental. More so than everything is like, every day counts. You got to just have a good outlook on every day. I feel very strongly you should not be angry anymore. Because if you see our patients with cancer who are so gracious, and that's the attitude that I love so much about blow lashes or lashes always upbeat. I think it's really important that every day counts and that no day spend in anger.

Aimee Sax:

I love that. So Josh, when people leave here today and they're eager to speak to a genetic counselor, where do you recommend is a good place to start?

Josh Barnhart:

Yeah, now that a good question. I keep saying good questions, but they’re all great questions.

Aimee Sax:

Hey, I love that.

Josh Barnhart:

I'm always happy to answer them as well. There's a couple of different ways. So the easiest way is, honestly you can go and type into Google and go to the specifically, it's called the National Society of Genetic Counselor page. And on there, they have specifically a way to find a genetic counselor in your area. So every genetic counselor is in that section, so you can click find a genetic counselor, type in your area and be able to find a genetic counselor. That way they'll pop up with names in your area. You'll be able to either message them, call them, or figure out an office number for them to contact as well.

Josh Barnhart:

Also, another way to go about it is primary care physicians are oftentimes, I should be aware of at least its local genetic counselor in that area as well. So you can always talk to your primary care physician as well, talking about, is there a genetic counselor you know of? Can I get a referral to go see them as well? So I think the easiest way oftentimes, because we all have phones nowadays, we all have iPads, things like that as well to be able to type into Google, like I said, it's called the National Society of Genetic Counselors. They have a find a genetic counselor page. You can go on that page, you can find one locally, as well as like I said, oftentimes primary care physicians can be a great local resource as well as oftentimes they're tapped into your specific region in terms of saying, "Oh, this is the local genetic counselor as well."

I know this is mostly for the Contra Costa region, but specifically in this region I think John Muir is one of the most local ones in terms of the genetic counselors here. So I'm part of a great team here. It's me and two other genetic counselors as well, but there's also, I believe now a genetic counselor in the Berkeley area, there's some in Oakland. So there's still some absolutely phenomenal genetic counselors all in this region, as well as throughout the entire Bay Area and all around the United States as a whole. So something that I think everyone is fantastic. So I'd always love to see everyone as well, but also I'm sure every genetic counselor as well, they're trained and they do a phenomenal job as well. So I'd always be happy about, I think everyone would be too. So I always-

Aimee Sax:

Absolutely, and I love that you mentioned all of those resources because actually one of our volunteers on our committee compiled a list of different resources, some of which you mentioned, and then there are a few more on there, including Sharsheret does have a genetic counselor on staff. And so a lot of people who aren't ready to talk to their doctors about it or aren't ready to have their insurance know that they're scheduling an appointment, you can always start with a confidential consultation with our genetic counselor and then she can help connect you to all the resources that Josh just mentioned. But we will be putting in my colleague, Jessica is going to put in the chat a flyer that we created of all of her research. This will also be emailed out to all of you. So don't feel like you have to click it now. Just know that it exists and it's coming to an inbox scenario. So Raleigh to close out our panel portion of the evening, what do you want to make sure everybody walks away from here today knowing about being a carrier for hereditary mutation?

Raleigh Zwerin:

Well, you said it, Aimee, when you said knowledge is power. I don't want anybody else to learn by chance or a dog the way I did about their genetic mutation. I want to make sure that people know this is a really personal decision, and depending on your age or your genetic history, it is a really different risk for everyone. And so everybody has to make that own choice. They may not want to be tested. They may not take the drastic measures that I took if they find out that they're positive. But what I hope that people will know is that that information and the education is so important so that you can make your own informed decisions about what you want to do for your own health.

And that I hope you will take the information that you've learned tonight, and you will share it with your families. You will share it with your aunts and your uncles and your cousins and your brothers and your sisters and your children and your grandchildren. And you will tell them that anyone can have a BRCA mutation, that if you are an Ashkenazi Jewish descent, that your risk is one in 40. You'll tell them that men and women can both be positive. You will tell them that there are fertility options for those people who haven't yet gotten pregnant and want to learn more because you don't have to pass this mutation

on, and you will tell them that there are incredible doctors like Dr. Pamela Munster, who is doing great work to make sure that there are better screenings, that there are better preventative options and there's better care.

Raleigh Zwerin:

Having a BRCA mutation and having to go into do surgery the way I did, I fortunate to be able to do, but it's not an option that I want my daughter to have to face. And I know that with time and research, that there will be much better options for our children and for our grandchildren.

Aimee Sax:

Absolutely. Thank you so much. That was such a beautiful way to end. And you actually said a lot of the things that I was planning to say in my closing. So I'm so glad that everybody got to hear it from you in such an eloquent positive light. We've learned so much from all of you tonight. We have so many questions. I cannot believe how active the chatbox was the full-time. So please know I have copied all of your questions. I will save the chat. We will get these questions answered, but definitely not tonight because we don't want to be here till 10:00 PM.

So before I begin the Q&A portion, I just want to mention that Sharsheret is trying to understand the effects of types of programs like these. So we can make them even more effective and helpful. To that end we will be including a link to a short survey in the chat. You will not be added to our email list because you click that link but you do have the option to opt into it. This is an easy, confidential way to help us continue to provide pre support. So thank you in advance for clicking that. Okay. So we're going to try to answer as many questions as we can, but like I said, we're not finishing them all. So just know that I will be following up in an email. So we've talked a lot about the main cancers that are associated with these gene mutations. Josh, can you speak a little bit about other cancers? We've gotten so many questions about different cancers, bladder cancer was very popular. In the questions we got colon cancer, was already touched on a little bit tonight, lymphoma, leukemia, and even anal cancer.

Josh Barnhart:

Yeah. So at least for these genes, or like I said, for these cancers specifically. Oftentimes there are genes that are associated with these cancers that have been mentioned. So for the colon cancer, for the bladder cancer, for anal cancer, there are genes that are associated with these cancer. They're not always these BRCA genes. Those are not ones that we currently know are associated with them. But as I mentioned, when we talk about genetic testing is we oftentimes talk about what's called multi-gene panel testing. So that means that we know of a lot of different genes that are associated honestly with a lot of different cancers. So absolutely for colon, for bladder cancer, like I said, for these other cancers, oftentimes we do know of genetic components for them.

With that being said though, not all cancers have some genetic components involved. As Dr. Munster had mentioned earlier, for breast cancer it's currently thought that about five to 10% of breast cancers have some genetic component. That's similarly for colon cancer, five to 10%. And it really varies per cancer. For ovarian cancer actually, that number is thought to be closer, to be 20 to 25% of ovarian cancers have some genetic components involved. So it's just to simply say that for a lot of these different cancers, there can be genetic components involved, but I always use that word can just because if you have that cancer doesn't mean that there is always some genetic component.

Sometimes cancer is simply just due to what we call sporadic factors, just meaning it's an accumulation of a lot of different things over one's lifetime that can lead to an individual actually having cancer. And sometimes it's not genetically related whatsoever, but something rather, like I said, just due to a lot of

different factors over one's lifetime. So it's the same. Absolutely for these other cancers that you mentioned, absolutely there are genetic components, but it doesn't always mean that there is some genetic component that is there for that specific individual cancer.

Aimee Sax:

Thank you. Dr. Munster, can you speak a little bit about the WISDOM Study? We've got a few different questions about this and someone who's watching tonight is actually participating through UCSF.

Dr. Pamela Munster:

The WISDOM Study was designed with the goal that, do excessive screening and imaging in women and not do sufficient screening and imaging in other women. So going back to the idea that if you have a BRCA1 or two mutation, you should start screening at 25. Obviously a mom or a grandma starting at 50 is not going to serve anyone with a BRCA mutation. On the other hand, someone with no family history of cancer and no mutation, we may not need to do a mammogram. Maybe you're starting at age 35 or 40 years, so some areas still do. So there's this uncertainty. So the WISDOM try to randomize this women into either doing extensive gene testing and screening versus not. As I said, again, I have mixed feelings for the WISDOM Study because in a high risk population, like Ashkenazi Jewish, I would much rather see every woman have genetic testing. And if you have a BRCA mutation, get appropriately screened rather than randomized to genetic testing versus not.

But at the same time, I don't want to sound unsupportive of the WISDOM Study, but as I said, I would have been poorly served with a randomization to not getting genetic testing done because particularly for my family, as I said, coming from a very small family, we know Ashkenazi Jewish background, for me having the mutation was not quite as readily understandable and I would have not been picked up, and needless to say none of my house care provider actually felt very strongly about me doing BRCA testing and I didn't qualify. So I think just want to drive home, how much my life and more importantly the life of my father who had pancreatic cancer lived six years with it, had really been impacted by this mutation. And I think I really had six extra years with my father because I knew he had a BRCA mutation I would not miss this. I think there was some important study for high risk population. I still would refer it to do genetic testing.

Aimee Sax:

Josh, we got a couple of questions about medical insurance. So one is what implications happen with your insurance if you do test positive? And another is what if my insurance won't cover a genetic testing because I'm not actually deemed high risk, what do people do in those situations?

Josh Barnhart:

Absolutely. So I'll start with what can be the implications for if you have a positive results. So there was actually a federal law that went into place in 2008, it's called the Genetic Information Nondiscrimination Act, which is a long name but it's simply just important that you guys know what it means or what it says. And what the law stated was that for your medical insurance and for your occupation, they cannot use your genetic information against you. So if you had a positive result came back, saying one of these BRCA genes and it says you're at an elevated risk, like I said, for your medical insurance or your occupation, they do not have the ability to use this information. However, what this law did not cover was specifically life insurance and long-term disability insurance.

So what the law stated, they say you currently have a plan, life insurance policy set in stone. So if you want to go get genetic testing, well, they can immediately then use information against you. Your policy

is already there, so it's set in stone. But what the law stated was that if you had a positive result and then you went to go update that life insurance or say you wanted new, additional life insurance, that they've been would have the ability to use that information against you by being able to say, okay, have you had genetic testing? Okay, I see that you tested positive. Well, therefore they may be able to charge you more, maybe able to flat out, deny you a plan as well. So in terms of, like I said, the medical insurance and the job, thankfully that is covered. Nothing that they could ever use against you, but in terms of the life insurance and long-term disability insurance, that is something that is not covered at this point in terms of if you went to go get a new plan or update a current plan.

Josh Barnhart:

In terms of though for the genetic testing, say you go and go get insurance or go and get genetic testing, I should say, and your insurance says, you know what? We're not going to cover it. What I will say is that most of the labs that we order through nowadays have what we're calling, these Patient Assistance Programs, to be able to say, to limit that cost of actually how much genetic testing is. So most labs have an out-of-pocket cost of about $250 nowadays. So most labs that we order through now have that 250 number to say, it isn't covered by your insurance, well, we're only going to charge you that 250 number.

And as I had mentioned, some of these labs have what are called Patient Assistance Programs as well to say, well, if you make with them a certain amount of money, and to say if you are getting any charge, it's 250. Well, there are actually sometimes even drop that number even lower than just that 250 number. So thankfully a lot of insurances have come a long way in terms of covering genetic testing. But absolutely we still run into roadblocks sometimes with insurance, but thankfully genetic testing, at least in terms of the cost has greatly lowered over the last 10, 20 years as well. So thankfully we're down to 250 and hopefully that number can only continue to go down in terms of the price that a patient can be charged, but something that at least currently right now, that number is that 250 number.

Dr. Pamela Munster:

Well actually Color has family testing for $50. If you have a family member with a mutation, you tell them and you maybe get tested for $50.

Josh Barnhart:

And going off of that too, a lot of these labs have, oftentimes if you have someone who has a genetic mutation, they'll do what's called familial studies and they'll test family members oftentimes for free, if one family member has had it as well. So it's that 250 number oftentimes, like I said, for individuals who are freshly new, I guess, to getting it, but absolutely if you have a family history, Dr. Munster is absolutely correct in saying that there are other options that can be cheaper as well, actually.

Aimee Sax:

Absolutely. This is a question for both Dr. Munster and Josh. We got a few questions about some other genetic mutations that we haven't touched on yet tonight. The BRAF mutation, It's implications and non-surgical treatment options, and also variants of the genetic mutations that we've talked about tonight, like K169ON. But I know there are lots of variants, so we can kind of talk about that. Whichever one of you wants to, yes Josh.

Josh Barnhart:

I'll talk about the variants first then I'll leave the BRAF up to Dr. Munster and talk about. I could talk about as well, but I'll leave that up to her. And saying that for these variants is that Dr. Monsters talked

about it earlier today, but that for all of these genes that we have, well, they all have possible different variants that do exist. And so for that specific variant, I won't lie. I do not know which gene that is and also I'm not aware of what specifically that is. I'll to do more research specifically to learn about that one. I can always get back to you as well. But in terms of, for these variants is, variants simply means that it's a genetic change that's out of the ordinary, and that's because we all have different genetic changes between us, but they're all just what make us unique for the most part. Maybe they make our hair color a little bit different, or eye color a little bit different. But having genetic changes isn't always a bad thing.

Josh Barnhart:

So occasionally when we find genetic changes, they are out of the ordinary, but occasionally we don't know what they do. We don't know what all genetic changes in our body do. So occasionally we can't find variants of what we call uncertain significance. Simply what that means is that there are genetic changes that are out of the ordinary, but we're not sure at this point whether it's actually causing that gene to not function correctly, which we call a positive result. Or whether it's actually just unique human variation, all just what making us a little unique, and it's actually more likely to be a negative results. So I said for that specific variant I promise you all I said, look it up and get back to you as well. But specifically for these variants just to say that thousands and thousands of different variants are possible and sometimes we don't even know what all variants do in all of these genes that we're testing for. So sometimes we just say they're uncertain.

Aimee Sax:

Absolutely. And Dr. Munster, if you want to say something about the BRAF mutation.

Dr. Pamela Munster:

Yeah, BRAF mutation is actually an important mutation in many cancers for most of all in melanoma. It's typically a mutation that's only seen on the tumor, not one that get passed on or inherited. It helps us select different treatment options for melanoma, sometimes colon cancer. And there's a very rare form of hairy cell leukemia, which is 90% BRAF positive, where we give BRAF inhibitors, specific medications. And then Josh, I really like your explanation about the variants of unknown significance. I mean, the challenge is people really struggle with this. And it's not just the variance of unknown significance, it's like if you have a strong family history but you don't know where it's coming from, it's really difficult.

So I actually have to say it's not a great thing to have a BRCA mutation, but it's a good thing for me to have a BRCA mutation because from my daughter she either has it, in which case she gets screened or she doesn't have it and then she's what we call the true negative, meaning my breast cancer risk is not passed on to her so her breast cancer should actually be same as a population lower. Whereas if your mother died at 35 for breast cancer and you have no idea where it's coming from, we cannot make any prediction for the offsprings. And so the cancer is going to [inaudible 01:05:43] within two mutations, actually, something really reassuring.

In the words of my son is like, who recently found out he has a BRCA mutation, he was saying, well, the good thing you didn't know that you had a mutation, otherwise you may not have had me. So Raleigh, I feel like I'm with two souls in my chest about the genetic testing and the pre-implantation diagnostics, because we're all here and we feel like our life is important. And so not having had us because you could choose. As I said-

Aimee Sax:

We hear that all the time, absolutely.

Dr. Pamela Munster:

Yeah, very difficult. And I have to say one of the interesting things, I have really interesting discussions with our young children. And I think, Aimee, it maybe interesting to have one of the younger generations on the panel next time to get a little bit more perspective how kids see this.

Aimee Sax:

Absolutely. I love that idea. And in the survey that we are sending out, we are asking everybody to share ideas for future panels and future programs. So I love that idea. And if anybody else has any other ones, I'd love to hear that too. Well, I feel like I could sit and chat with you all night but I do see our participant numbers are going down. So I think we should save the rest of the Q&A questions or that follow-up email. But I just have to thank all the members of the panel, all the members of the committee, everybody who's joined us tonight, we're making this evening such a success. I really am just so touched by everything that everyone said. And I feel like I've learned so much. The one question that we have gotten a few times, even though I did hear our panelists speak on this is, should people who are older, 60, 65 and above still consider genetic testing. So let's do that one last question and then we'll close it out.

Dr. Pamela Munster:

Yes.

Josh Barnhart:

Yeah. For sure.

Aimee Sax:

Thank you. Perfect. Short and sweet. And absolutely anybody who's looking for more information, you can connect them with Sharsheret's genetic counselor. You can connect with Josh, you can connect with all the different genetic counselors on the resource page that we are going to share. So thank you all so much. I've learned so much tonight. I know everybody's probably learned a lot tonight. And I know that just like Raleigh said, we all have family and friends who we should have this conversation with and share at least one or two things that you learned tonight. And then also I'll be sending out the recording of this event in the next week or so. And so feel free to share the recording, because like I said, we are in all 50 states and this information is helpful for people around the globe.

If you are due for any healthcare screenings, mammograms, genetic testing, or even the dentist, I know we're all a little overdue this year because of COVID and worries about that. But please know that doctors, offices, dentists, everybody like that is a COVID safe environment, they're all taking it more seriously than anybody else and it is time to reschedule those appointments that you may have missed. And please get in touch if there's ever anything that Sharsheret can do for you. We are here for everybody regardless of background so don't hesitate to get in touch. And now Jackie has some closing words to share. Thank you all so much.

Jackie:

Hello. Behalf of all of our wonderful sponsors, I'd like to thank our panel members, Dr. Pamela Munster from UCSF BRCA Research Center. By the way I saw your NOVA a few months ago, I really enjoyed seeing you in my program. Josh Barnhart, our genetic counselor from John Muir Hospital, one of three as you said, I look forward to getting to know you. And Raleigh Zwerin, I really appreciate your coming on and telling your personal story. I also want to thank Aimee Sax, of course, from Sharsheret for her invaluable input into our Under One Tent program this evening. And most of all, to you, our community for attending this very important discussion on hereditary genes.

I trust that you've learned something new about genetics. Although the conversation was predominantly an Ashkenazi Jewish issue, we need to educate our families, friends, and the community about how we can prevent this mutation in future generations, and how testing is readily available. This is a very important public health issue that needs to be addressed. Please note where you can go for your genetic testing and counseling. And as Aimee mentioned, you'll be getting more information if you've not already taken the information from the chat. Again, thank you for your participation this evening. And for further information about upcoming Under One Tent programs, please contact underonetent@ccjcc.org. Good night, stay well, and keep smiling.

Aimee Sax:

Thank you all so much. Take care.

About Sharsheret

Sharsheret, Hebrew for “chain”, is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret’s Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

- The Link Program
- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer • Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors • Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer • Sharsheret Supports™, developing local support groups and programs

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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