From Risk to Action Navigating Hereditary Cancer Genetic Testing

National Webinar Transcript

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Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

About Sharsheret

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

With regional offices in the Midwest, Northeast, Southeast, West, and Israel, Sharsheret serves 275,000 women, families, health care professionals, community leaders, and students. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, approximately 25% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

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

Sharsheret offers the following national programs:

The Link Program

Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences

- Embrace™, supporting women living with advanced breast cancer
- Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors
- Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

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Jessica Jablon:

Hello. Welcome everyone. Thank you so much for joining us for today's webinar, From Risk to Action: Navigating Hereditary Cancer Genetic Testing with Sharsheret and JScreen. I'm Jessica Jablon. I'm the director of the West region of Sharsheret.

We want to begin by thanking our sponsors, Ambry Genetics, AstraZeneca, BRCA Initiative of Colorado, JScreen, Cooperative Agreement 24-0061 of the Centers for Disease Control and Prevention, and the Florence and Joseph Appleman Lecture Series who have made today's webinar possible.

A few housekeeping items to start us off. Today's webinar is being recorded and will be posted on Sharsheret's website along with a transcript. Participants' faces and names will not be in the recording. If you would like to remain private, you have the option to turn off your video and rename yourself, or you can call into the webinar.

We also have closed captioning available. To display live captions on the bottom bar, click on "captions" and then click on show captions.

You may have noticed that you were muted upon entering the Zoom. Please stay muted during the call.

We are going to be holding a Q&A at the end of the presentation, and if you have any questions, please type them in the chat box and we will do our best to get to as many as we can during the Q&A.

I want to remind you that Sharsheret is a not-for-profit cancer support and education organization and does not provide any medical advice or medical procedures. Our full medical disclaimer is in the chat.

As you hopefully know, Sharsheret is constantly offering webinars on a variety of topics. You can find our upcoming webinars and link to our library of past webinars in the chat. You can join our series of yoga webinars that are happening right now, the next one is this Thursday, December 11th, to feel relaxed and rejuvenated through movement during our Tranquil Thursdays. And the registration for that is in the chat.

If you are facing a breast or ovarian cancer diagnosis, you don't have to face it alone. Sharsheret is here for you and your loved ones. Sharsheret provides emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience. All are completely free and confidential, and our contact information is going into the chat now.

Now, before we welcome our genetics experts, I'd like to introduce Shelly, who will be sharing her story today.

Shelly:

And thank you. Thank you for asking me to join you.

About three and a half years ago, I was tested with JScreen. And that came about because I had a, at that time, 10-year-old great niece, my brother's granddaughter, who has some developmental delays and some very small stature, and they wanted to see if she had any particular genetic disorder. So she was tested and she came back positive for a genetic disorder, but also positive for BRCA1. And at the time, no one in her family had a history of breast cancer. And unfortunately, her mom and grandmother had already passed away, so she had nobody to check with on her side of the family.

And I didn't think much of it because my mother and cousins, nobody had had any cancer experience. I have a cousin who later had breast cancer, but she's not BRCA1 positive, so it just never occurred to me. But my niece wouldn't let it go. She herself went and ended up getting ... She was in her mid 40s at the time, she got a hysterectomy prophylactically. And she wanted her father, my brother, to be tested. And he started looking online and JScreen reached out to him. Search engine optimization is a powerful thing. And he ended up getting himself tested by JScreen, and he came back positive. So I said, "Well, if he's positive, I need to get tested." And I was 71 years old at the time and he was 74.

So I contacted JScreen, he had sent me their information, and they sent me the kit; and I sent it back, and lo and behold, that came back positive. And I had been tested at mammograms every year since I was 40, so at 71, it would be a real surprise to me that there'd be any problem. But I spoke to my then gynecologist and I spoke to my doctor, and they said, "You should go see a breast specialist. They should handle your testing from now on." So I did. And the doctor said, "Why are you here? You're 71 years old. Why did you do this?" And so I explained the story and she said, "Well, let's do an MRI as a baseline just to be certain."

And so I had just retired in April, and this was in June. This was in 2022. And they did the MRI and it came back with three small spots in my left breast. And they did a biopsy, and lo and behold, they were cancerous. So instead of having a summer of travel, I had a summer of a lumpectomy, and then six months of chemo and then radiation.

And along the way, very soon after the diagnosis, I was talking to someone, a friend locally, and they reminded me that Sharsheret had given a presentation at our synagogue quite a few years ago, and I should look them up online and see what they're still doing. And I did, and they sent me all kinds of material, which felt great, even if not every bit of it applied to what I was doing at the moment, but it felt great not to feel so alone, and they were super throughout the entire process. Particularly their ability to talk to a social worker along the way helped my sanity stay in check during the worst of the chemo and the worst of going through it.

And I'd also talked with a genetics counselor from JScreen during that initial process also, and all those pieces definitely helped me try to stay focused and realize that lots of people had gone through this and helped me realize I could try to make it too.

So it really saved my life getting that diagnosis because my mammograms were normal, and my doctor even told me that if she had just looked at my mammogram, she would not have known that I had cancer at that point. And I wouldn't have gone for an MRI, but they wouldn't have sent me without that. So I'm very grateful that it existed and it helped me get to where I am. And I'm three years now without cancer, so I'm very happy about that. So thank you.

Jessica Jablon:

Thank you, Shelly, for sharing your story. It's really powerful what you've been through and we really appreciate you being here today to share it with all of us.

Now I'm excited to introduce Karen Grinzaid. Karen is the Founding Executive Director and Chief Clinical Officer of JScreen, where she has been a leader in providing accessible genetic testing and counseling with a genetic counseling background and over 30 years of experience in the field. She is also an adjunct associate professor at Emory University, where she teaches a mentor's genetic counseling students. She also holds a master's degree in human genetics from Sarah Lawrence College and certifications from the American Board of Genetic Counseling and the Association of Clinical Research Professionals.

Karen Grinzaid

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Thanks Jessica.

Jessica Jablon:

Karen, I'll turn it over to you.

Karen Grinzaid:

Thank you.

And thank you so much for sharing your story, Shelly. It just warms my heart because this is the work that we do every day, and we try to give information that will help prevent problems later for people and it's really wonderful. And also that you found Sharsheret. We try to work with Sharsheret to be able to offer testing to people, but also support services and follow up. So really amazing.

So I'm going to share my screen and ... Okay. I'm going to give just a little bit of an intro about myself and kind of what got me started in working with the JScreen program.

So again, I'm a genetic counselor by background. I've spent many, many years in clinics working with families that had different genetic issues, maybe children with genetic problems or couples that were pregnant, looking for testing to ensure that the baby was going to be okay or testing prior to pregnancy; and also worked a little bit on not only the diagnostic side, but also the therapeutic side, but really got interested in the prevention side because I saw so many families that either had a child with a genetic disease or a cancer developed in the family, and had the family had information about their genetics, these problems could have been prevented, or at least they could have known ahead of time. And that's what really led me to get this JScreen program started to get prevention out there and make it accessible to people who needed it.

So the JScreen program, I'm going to talk about it at the end because I want to give people a background about genetics and cancer. But we started this program back in 2013 as a national community-based public health initiative dedicated to preventing Jewish genetic diseases and then focusing also on other communities as well.

Originally, we were based out of Emory University and just last year spun out as our own nonprofit or 501(c)(3), but still affiliated with Emory in a lot of ways, as you heard. And again, the goal of the program was to give people access to this type of testing and genetic counseling services across the country.

So when we think about cancer, you know, some people think about genetics and some people don't. And really the truth is that the majority of cancer occurs sporadically where maybe related to environmental factors or maybe we just don't know why, but not related to hereditary factors. But about five to 10% of the time it is hereditary. And this applies to most different types of cancer like breast or colon, different types of cancer.

And what do we mean by hereditary? By hereditary, we mean that there's a genetic change or mutation that a person is born with that increases their risk for developing cancer. So that gene doesn't mean that you will get cancer, but it's increasing your risk, that mutation is increasing your risk over the general population risk.

And you'll see on the right side that we see a family where ... Well, that looks like cancer cells where you see it coming down from generation to generation. We'll talk about that more a little bit later.

So what are some clues that there may be hereditary cancer in a family? And we try to talk to primary care doctors about this as well. If you see early onset cancer, so you see people in the family getting cancer, say in their 20s, 30s, 40s; if you have two or more people in a family that are diagnosed with the same type of cancer, really rare forms of cancer; also as you saw in the last picture, multiple generations of similar or even different types of cancer; and then certain types of cancer appearing together.

So we'll talk about the BRCA gene, which people have heard about. So in a family where a BRCA gene's being passed down, you might see breast, ovarian cancer, even prostate and pancreatic cancer, so looking at men and women, but those can all be associated with the same hereditary form of cancer in a family.

But then it gets a little bit tricky because sometimes you can have a cancer gene mutation and what looks like a cancer-free family, which is sort of what Shelly was referring to in her family, where there was nothing really suspicious and then a change in the family was detected.

So why is that? Well, it can happen for a number of different reasons.

Number one, maybe small family size. So let's say my husband's family, both of his parents were an only child. You know, so you're not getting a lot of history with a lot of people in the family. Maybe there's limited information; a person was adopted or they've lost contact with one side of the family. Maybe if we're looking at cancers like breast, ovarian, there are lots of men in the family where even if somebody had a mutation, maybe it hasn't expressed itself in family members. And also these are things that people don't always talk about. So maybe people in the family had cancer and just didn't tell anybody, went through therapy and just were embarrassed or didn't mention it.

And also, as I was indicating before, just because you have a mutation doesn't mean that you're going to get cancer. It means your risk is increased. So there may be people in the family with mutations that haven't had cancer, so you wouldn't notice that.

So I'm going to give the example of the BRCA1, or one of the BRCA genes, and what that can do within a family. Because as I said, it increases your risk, but it's not 100%.

So let's say you have a family where people are BRCA carriers. If it's a female, having a mutation in that gene increases that woman's cancer risk from about 13%, which is general population risk, anybody can get breast cancer, to up to 80 or so percent, which is a significant increase. Ovarian cancer, which is relatively rare, 2% of women will develop ovarian cancer, but with a mutation, that risk can be much higher, say around up to 50%. Prostate cancer in men, the risk is somewhat increased. Pancreatic cancer is also rare, but there’s increased risk. And men can get breast cancer, although much less common, and it increases that risk as well.

So this is just an example of a cancer gene where a mutation can increase your risk.

People are probably also familiar that the chance of having a BRCA mutation is significantly higher or about 10 times higher in the Ashkenazi Jewish population, so Jewish population from Eastern Central European countries. And that risk is about one in 40 in Ashkenazi Jews, which is about 2.5%. So that's significant.

We were actually interested in JScreen in looking at whether, with a clean family history ... Because we keep talking about, "Oh, I don't see anything in my family." So let's say there's a person who doesn't meet testing guidelines, but they have Ashkenazi Jewish background, we were interested in finding out whether that person has an increased risk as well with a clean history. And we studied 500 people from the Atlanta area where Emory's based with Ashkenazi

Jewish background, didn't meet testing guidelines for BRCA testing, tested them; and in fact, we found out that their risk was higher than the general population, so about one in a hundred. So based on ethnicity alone, this is a higher risk population for BRCA mutations.

Also, I want to emphasize, and we get so many questions about, "Oh, I already had BRCA testing. I don't have a genetic risk," that there are many other genes that are also associated with risks for these types of cancers. And the longer we go in time, the more information that we have. We're able to find even more changes even within the two BRCA genes, but also there are mutations in other genes, as you can see. And so if a person had genetic testing, say five years ago, they should look at the testing that was done or speak with the genetic counselor, because chances are they could get retested and update their testing, and you'd want to do that to make sure that there aren't other changes there that would be relevant for you and your family.

Talking here about breast, ovarian and other types of cancer, but there are other genes that are involved in other types of cancers as well, for example, colorectal cancer, stomach, skin cancers, melanoma. So there's genetic testing out there that looks at a panel of genes. For JScreen now we're looking at 63 different cancer-related genes that can help determine risks for different types of cancer as well.

And sometimes we'll find that a person who has a family history of breast cancer, not coincidentally, but sort of unrelated to that, will come up with a positive for a gene for colon cancer, which is also important for their health. So sometimes this more expanded testing can be really informative.

Different uses of genetic testing. And I know there are people on the webinar that have probably had genetic testing or could have genetic testing for a couple of different reasons.

So the first reason would be for prevention. So this would be a person that does not have a current cancer diagnosis and would be doing genetic testing to find out if there's something that they could do in terms of screening or something that they could do in terms of reducing their cancer risk.

So let's say a person came through for genetic testing, didn't have cancer, tested positive. Let's use, again, the example of a BRCA mutation. So now we know, let's say it's a woman, that they have an increased risk for breast, ovarian, and pancreatic cancer. So they could do increased screenings, and Shelly referred to this, to help rule out a cancer existing at the time, so through mammography, through breast MRI, as Shelly mentioned, and do that monitoring every six months to see if there were early signs of cancer so that they could intervene.

Somebody might also decide with the BRCA mutation that they don't want to go through that screening, that they would rather do something more preventative from the beginning, or do screenings for a while and then preventative, and elect to have a mastectomy or after childbearing to have their ovaries removed to significantly reduce those cancer risks.

Same for testing positive for a colorectal cancer gene; more frequent colonoscopies looking for polyps that could be removed or early signs of cancer. So these are all proactive things that you could do with genetic information.

For an individual that does have a cancer diagnosis, genetic testing can sometimes inform surgical decisions and also more effective treatment. So for example, in a person with the BRCA mutation, again, as I mentioned, they might consider ... Well, if the doctor was talking about mastectomy, there may be then a decision to do a bilateral mastectomy because we know that with the BRCA mutation, the risk for cancer in the other breast would also be increased. So again, that would be proactive to do that surgery instead. And again, as I mentioned, preventative removal of the ovaries after childbearing.

Treatment-wise, and I'm not going to go into detail about this, but there's certain medications that can be more effective in a BRCA carrier. And these are PARP inhibitors that preferentially kill cancer cells in someone with a BRCA mutation. So genetic testing can be really important in these individuals.

And I think a lot of people are probably familiar with this as well, but how are these cancer gene mutations inherited?

I know when we speak to people ... And maybe because they're used to JScreen. We originally started not in cancer genetics, but as a reproductive carrier screening program, helping couples get information about diseases like Tay-Sachs and cystic fibrosis. So a lot of people think of genetics as needing to have two parents who are carriers in order for a person to be affected. But in fact, cancer gene mutations are passed down in what we call a dominant way, where if an individual has a mutation in a cancer gene, each of their children is at 50% risk of having that mutation and also having the increased cancer risk.

We also need to think of it as male and female. So a male can pass on a cancer mutation to his sons and daughters, and a female to her sons and daughters. So when we think about genetic testing for a family for cancer genes, we need to be testing both men and women. And a lot of people don't realize that, but the men also can carry mutations and can also have increased cancer risk and pass that down.

So how do families use that information? I think people can be surprised that some people even use this information for family planning. So we see a lot of families where there are multiple family members that have been impacted by cancer and they're thinking, "My gosh, I don't want to pass this mutation down. I really want to stop this genetics in its tracks and not have my kids have to deal with the genetic risk if possible." And those individuals or couples can use in vitro fertilization to significantly reduce their chances of passing that mutation onto their children.

And the way that that's done very basically is you take eggs from mom, sperm from dead fertilized outside of the body through a reproductive endocrinologist or IVF specialist, and select the embryos that don't have the mutation and use those for a given pregnancy. So you're getting pregnant then with the embryo that does not have the mutation.

Another way around this is to, let's say it's a woman who carries the mutation, to get an egg donor who doesn't have a cancer mutation for the pregnancy. Some people like to do testing during the pregnancy to find out if the baby would be affected or have the mutation, and then some people who like to adopt instead.

So how do you access genetic testing? There are a lot of different ways, and all of these ways are good ways.

You could go to your doctor and tell them that you're interested in doing genetic testing and let them help order a genetic testing panel. It's a good idea to go to a doctor who understands about cancer genetics and knows what type of testing to offer because you want to make sure that the testing addresses family history concerns, ethnicity-based concerns, and is a nice expanded genetic testing panel; and has the ability to talk to you about the results or access a genetic counselor to help do that.

Someone might schedule an appointment at a genetics clinic, speak with a genetic counselor, review family history, and they would order the testing for you. Sometimes there can be long wait times for appointments, but that is a very good way to access testing; or remotely via Jscreen. And I'll talk about how we're making that testing easy and is another good route to access testing.

So what we were trying to do when we created the program back in 2013 was ... And back then it was a little bit of a crazy idea. Now it's more normal because of COVID and letting people access testing from home. But we really wanted to take down barriers to genetic testing. We didn't want people to have to wait for an appointment, to have to go somewhere, to have to talk to somebody, get their testing done, wait, have to go back and talk about it again; to let people do everything from home. But to do it under medical guidance and not do it in a direct to consumer way, and make sure that the testing is comprehensive.

So the way that it's done is a person would go online to jscreen.org, they would get a lot of information about genetic testing. You'll see that they'll have options for reproductive genetic testing for things like Tay-Sachs that's separate or hereditary cancer testing, or both; order the testing. It's under a physician order that we facilitate, a genetic counselor reviews all the information. There's a cancer family history form that you fill out online and you enter your insurance information.

If everything's okay, you receive a saliva kit by mail, spit in a tube, send it to the lab, the testing is run, then the results are released with an opportunity to speak with a genetic counselor, which we strongly encourage, particularly for people with positive results or variants, so that the person understands their results and next steps. Part of that process is if somebody has a positive result, we're referring to Sharsheret if relevant for support services as well.

Again, we talked about the panel that we offer that includes over 60 cancer susceptibility genes covering many types of cancer. We like to really restrict cancer testing for individuals who are 21 years and older. You could test down to age 18, we don't test minors, but we say 21 and up because we want to make sure that the person's ready for that information, and also that the information is actionable, that there's something then that you'd be able to do to help prevent cancer.

We'll test men, women, of any ethnic background. And you can test from any state in the United States. We can mail a kit to anywhere in the United States.

Just very briefly, if a person were interested in carrier screening for reproductive purposes, we have a big panel and we test people of reproductive age. Ideally prior to pregnancy, and I want to emphasize that because if you do that testing prior to pregnancy, you have more options to get around a genetic risk to future offspring, like IVF, which we talked about.

So we've been working with Sharsheret for a long time, and I'm excited. We do in-person events together, and we try to get information out and share information about our services. If you register for a genetic test, there's a coupon code that you can enter at checkout, which is Sharsheret18, which will take $18 off our upfront fee. The upfront fee covers the genetic counseling services, which follow you all the way from registration until the genetic counseling at the end, and also a physician order for the testing.

The lab test is then billed to your insurance, which often covers the cost of testing if you meet guidelines. There's also a self-pay rate of $249 if insurance doesn't cover their deductibles or copays or you just don't want to go through insurance, and financial assistance programs for people who qualify who can't afford to pay. We want to make sure we're taking down barriers to testing in whatever way we can. And there's a support email and phone number for questions about billing.

So if you're interested in testing and want to just go to that QR code or our website at jscreen.org, we're happy to help you and answer any questions.

And my contact information. I know Peggy's going to address some questions, or we're all going to address some questions at the end, but any questions you have and you want to contact me directly, I'm happy to help.

Jessica Jablon:

Thank you, Karen.

Karen Grinzaid:

Thank you.

Jessica Jablon:

And now ... Thank you, Karen. I learned so much from you, and we really appreciate you sharing today about JScreen and how it works and all of the things that you shared.

And now I'm excited to introduce Peggy Cottrell, one of Sharsheret's genetic counselors. Peggy is our Genetics Program Manager and is a graduate of the Sarah Lawrence College Master of Science in Genetic Counseling Program. At Sharsheret, Peggy consults with women and families and answers individual questions about their family histories, BRCA mutations and personal risks of hereditary breast and ovarian cancer, and contributes to the development and implementation of Sharsheret's hereditary cancer resources and programs.

So Peggy, I'll leave it to you.

Peggy Cottrell:

Thanks so much, Jessica. Give me a second to share my screen.

So I want to start by just addressing a couple of questions in the chat, first of all to say that we're not taking a lot of time to talk in any detail about any specific mutations. I do want to mention that Lynch syndrome and CHEK2 and BARD-1 and some other things that people have asked about are definitely on JScreen's panel, and if you're a carrier for those, they're going to identify them. And how we take care of people with specific inherited mutations is going to vary from one person to another, depending on their personal history, depending on the specific mutation, their gender, and lots of things.

So we're not going to spend a lot of time talking about all of those details, but I do want you to know that I will get a copy of the chat and we'll look at the questions that were in registration, and if there's anything that we don't get to, I will send something out.

I want to talk specifically, and I think Karen spoke about many of the things that we do differently for people who test positively. So sometimes people say, "Well, Peggy, I'm not going to remove any of my organs. Do I really need to do this test?" And the reason is, yeah, this is a great test to do because it changes the type of screening that you get. And we learned already this evening from Shelly how much of a difference it made for her to be able to get that MRI, which was not something that would've been ordered under other circumstances. So it is really important to find out that information.

Healthy living is going to help people live longer. Chemo prevention is using a medication like Tamoxifen, even if you haven't had cancer, to prevent the development of breast cancer. There are prophylactic surgeries that can be chosen to reduce risk of developing cancer. And we mentioned the pre-implantation genetic testing to prevent passing the mutation to the next generation.

But I want to really concentrate here on what we can do for you at Sharsheret. And myself and Bianca, who is on the call tonight, we're both genetic counselors who work at Sharsheret, and we both talk to people who have questions like you've posted in the chat today. And a lot of what we do ...

So one of the things we don't do at Sharsheret that we use our partner JScreen for is order anyone a genetic test. We don't have any ability to do that. But we can help answer your questions. So if you want to schedule an opportunity to speak to one of us about whatever your questions are, you can absolutely do that and it's free of charge.

We're also able to connect with multiple family members at the same time. And I will tell you, I have spoken to as many as seven or eight people at the same time. More typically, usually I only talk to one person at a time, but two, sometimes three. And sometimes it helps to get sisters together or a couple who wants to talk about fertility and PGT to be able to have that kind of conversation and we can facilitate that.

We have a peer support network, so we can hook you up with someone who went through something that you're about to go through. So if you are thinking about having a risk reducing mastectomy with a free flap reconstruction and you have kids at home, and you want to talk to somebody else who's been through that, and, "Oh, by the way, can they please be Jewish or a certain type of religious level of practice?", we have those people available who are just waiting to be able to speak to you.

We have parenting resources. And many women have said to me, "I would go through another surgery if I didn't have to think about what it means if my children have inherited this from me." It's very hard to find the strength to be able to explain this to your children, and we have resources that can help with that.

We have something that we send out to people who are undergoing treatment, perhaps a risk-reducing surgery, or for people who have cancer, chemotherapy, that we call a busy box. And it has toys in it for kids ages two to 12 to keep them busy while mom is trying to recover and get her strength back.

And we send parenting resources out as well. In fact, we send out a book that's named something along the lines of "Why Is Mommy Going To The Hospital? She's Not Even Sick", And this explains a little bit about prophylactic surgery in a developmentally appropriate way. And I know many parents will tell me, "Look, I didn't feel like I could actually show my children the pictures in this book, but hearing how the book explained about this kind of surgery in a child's way of thinking really helped me to be able to explain it to them even without this book."

We have PGT resources. So we have a webpage where you can go and read about how this process works. And we have a PGT kit now that has some written information and resources and a candle and a notebook, but also a case to carry the medications that you might end up having to travel with to give yourself a shot possibly while you're at work, so with a little cooler bag in it.

And finally, we do webinars like tonight on dozens of topics, and very often we can send these out after the fact. So they're all archived on our webpage and I send people, if they're thinking about removing their ovaries, I have a great webinar that they can take a look at. So these are all resources that we have that are available to you.

And one of our new exciting resources is that we now have a page that we are syndicating from FORCE, which is Facing Our Risk Of Cancer Empowered, where we have specific information about more than 20 different genes that are predisposing to hereditary cancer. And so you can click on this site and click on the particular gene, and the Lynch syndrome genes and BARD-1 and CHEK2 are all on our webpage now. This is a page we've had up for just a couple of weeks now. And so we're really excited about that as well.

So please don't hesitate to reach out if you have any specific questions about your unique mutation. We can help. We know how to talk about Lynch syndrome, we know about BARD-1, we know about CHEK2, and we can absolutely help with those.

So I think at this point we can move on to the question and answer aspect.

Jessica Jablon:

Yes. Thank you both so much for sharing and giving all of these resources to everybody who's on the webinar. I put in links to the PGT page and to the cancer gene page that Peggy mentioned into the chat, so you can find those there.

Please remember, we cannot address questions that reference uniquely personal situations. There are a few questions that came in, and like Peggy mentioned, our clinical staff will reach out to you about those particular questions.

But we did get a lot of other questions that came in, starting with, "How early can we tell our family members, male or female, children, nieces, nephews, grandchildren about genetic factors and urge them to get tested, specifically if a parent is known to have a mutation?"

Peggy Cottrell:

So I have ... You know, over the years of speaking to different families, what I find is different families deal with this in different ways. And I can think of one caller I had who from the time her kids were first born, she had had breast cancer, she had a BRCA2 mutation, and she wanted to talk about it from the very beginning to normalize it. So like the way you would tell a kid who's adopted that they were adopted right from the very beginning so it doesn't have to be an announcement.

I don't think that's the way most people deal with it, but you could really do something like that. Or you could wait until your children are older. Probably somewhere between 18 and 21 is when you really want to definitely think about starting to do this. And that's because those are the ages where, and again, it takes some time to get used to the idea that there's this inherited mutation in your family. And nobody is tested younger than 18 for the most part, and what I find is that there's a level of maturity that happens between 18 and 21 that really makes those ages better, and I totally get JScreen's idea to really think that 21 is a better age to start thinking about this.

And your job as a parent when you're telling your kids about this is not so much to tell them what to do, but to share with them what's in the family, that you got tested and that you tested positive, and that it's something that they can be tested for, and why it was important to you to be tested and what you were able to learn from it. But once your kids are adults, if you get too bossy about trying to make them do something, that is sometimes not a good approach.

So you want them to understand that this is a good thing to do and they can reach out if they have questions, they can reach out to us at Sharsheret and we're happy to answer those questions.

Karen, I don't know if you want to add anything to that.

Karen Grinzaid:

No, that's perfect.

Jessica Jablon:

Someone in the chat wrote, "Please touch on people who get similar cancers that are in their family, but they did not test positive for any known gene mutation while there are known gene mutations in their family." So it looks to me like there are similar cancers, but the genetic mutation is not there in the family with some of those people, but they also have the genetic mutation as well.

Peggy Cottrell:

So I think most of the time people who don't carry the mutation in the family don't have the increased risk that goes along with the family history, but it often depends on the particulars of the mutation.

And absolutely, it can happen that someone can have a cancer that goes along with the inheritance and it happens by chance. And when I was very early on in my genetic counseling career, I had worked with a family where there was young breast and ovarian cancer, and the person in the family who had the ovarian cancer had much better insurance, so she got tested on behalf of the rest of the family, this was when testing was very, very expensive, and she tested negative. And we were surprised. It was a Jewish family with young breast and ovarian cancer. And it turned out, later on we discovered that the people with breast cancer tested positive. So there was a BRCA mutation in the family that was causing this, but meanwhile, a family member got ovarian cancer even though they didn't have the mutation. So that can happen by chance, people do get cancer.

But sometimes in families, and here I'll mention CHEK2, sometimes in CHEK2 families in particular, we see it's not unusual for there to be other factors that are predisposing to cancer in those families besides CHEK2. So sometimes families with CHEK2 mutations have a pretty low risk; elevated above the population risk, but not hugely high to get breast cancer. In other families we see there seems to be a much more increased risk and we feel that there's probably something else there that we don't know how to look for. And that can happen in any family.

And so it's always a good idea to be cautious about your screening regardless of the results you get back from testing in a family, but you probably want to avoid doing a risk-reducing surgery if there really isn't an indication to do that.

But always discuss these with your genetic counselor and with a doctor because I would want to take a look at more details than what you're explaining. And I know you can't explain everything that's going on in your family in the chat box, but certainly feel free to be in touch with us.

Jessica Jablon:

Thank you, Peggy.

Another person asks if a saliva test is as accurate as a blood test to determine BRCA1. I'll just make it a little more general and say any genetic mutation.

Peggy Cottrell:

Karen, would you like to answer?

Karen Grinzaid:

Yeah, it should be just as accurate. On either sample, they're extracting DNA and they're doing a DNA or molecular analysis. I would say the only difference between the two is if you submit a saliva sample, a small percentage of the time, they'll need to recollect the sample because they don't get a good DNA sample from it, but the majority of the time it works and they're just as accurate.

Jessica Jablon:

Thank you.

Karen Grinzaid:

And from home, it's obviously easier.

Jessica Jablon:

Right. No, definitely getting the little box in your mailbox is a lot easier than having to go in someplace and do blood testing.

Peggy Cottrell:

And I think all of the major labs now have blood kits and saliva kits. So this is not something that's done only because JScreen is working through the mail. Even if you meet with someone in person, they usually carry both kinds of kits.

Jessica Jablon:

Peggy, just off of that question, someone asked how we contact you.

Peggy Cottrell:

Somebody can ... I can do it when I'm not talking. I'll put my email address in the ...

Jessica Jablon:

Right. I thought maybe you'd want to say your email address just so that it's on the transcript.

Peggy Cottrell:

Yes. So it's pcottrell@sharsheret.org.

Jessica Jablon:

Thank you.

We also got a question about insurance. "Should we consider getting life insurance for my 21-year-old daughter before she's tested for BRCA1?"

Peggy Cottrell:

So-

Jessica Jablon:

Karen or Peggy, either way.

Peggy Cottrell:

Yeah.

So it is against the law for there to be any problem with medical insurance, and that's the most important law that protects you from losing your medical insurance if you have a genetic mutation. There is not such a law in most of the country. I think there is a law in Florida, which is the only place where if you have a genetic mutation, you can still buy life insurance. Not every life insurance company is going to ask the question because lots of people have told me they didn't have trouble, but lots of people have told me they have had trouble. So if you have the opportunity to set up life insurance before you have the genetic testing, that's a reasonable thing to do.

But the important thing to remember is that you don't want to risk taking good care of your health because of life insurance. Life insurance is certainly important, but if people don't have it, they're not going to die from it. But if people avoid a genetic test because they're worried about life insurance when it's something they really need, that can be a problem.

So sometimes people are able to buy insurance in a group, like through a workplace, without a medical exam, and sometimes that can be a workaround. But you can talk to your insurance agent and see how they can help you.

Jessica Jablon:

Somebody asked, and Karen, you alluded to this a little bit when you were in your slides, "I've been doing genetic testing since 2009. At this point, my entire immediate family and many more of my distant family have been tested. How often, if at all, should this testing be repeated? And do the testing companies ever want to hear about our updated health status to try to determine if there is something to learn from our updates?"

Karen Greenside:

I can answer that.

So the important thing is the best way to do this is to talk to somebody like a genetic counselor who can look at your report and see if there's additional testing that's available and to update your family history. So it's both the technology and the history which can inform whether additional testing is possible or needed.

Jessica Jablon:

Thank you.

Somebody asked, "Should a 68-year-old male with Ashkenazi Jewish parents be tested, and what are the pros and cons?"

Peggy Cottrell:

So certainly national guidelines would recommend anybody with at least one Jewish grandparent, Ashkenazi Jewish grandparent, can consider this testing even in the absence of family history. And the likelihood that that person is going to test positive is small. So the question is always, "How is this information going to be helpful?"

And so if this gentleman has children or grandchildren, then he might want to have the testing. Maybe it's not going to be super helpful for him, but maybe it's going to be helpful for offspring. And certainly people do get cancer even later in life, and maybe there certainly would be different screening that would be done for somebody who tests positive even later in life.

And I think the difference now, I know when I was first doing this kind of work and the test cost thousands of dollars, it was kind of hard to really recommend that people who had a very small risk really pursue this testing because it wasn't going to be covered by insurance. And it's unlikely that in the absence of a family history that this is going to be covered by insurance. But because we have a partner like JScreen where we can get someone a genetic test for a cash price of $280, I'm not saying $280 is nothing, but it is something that's within the reach of many people who worry about this.

And what I often say to people, if you're asking me the question, "Do I need this test?", then I know you've been thinking about it and it's taking up space in your brain. And if you get the testing done, you're likely going to be reassured that this is not something you have to worry about, but if it is, you're going to have done something very, very important for yourself and for your family by finding out that information.

So again, it's a matter of weighing those pros and cons and the cost and seeing what makes the most sense.

Jessica Jablon:

Thank you. I feel like that was the perfect way to end our webinar. So thank you so much to Karen and Peggy, and Shelly for sharing her story.

We want to thank our sponsors again, Ambry Genetics, AstraZeneca, BRCA Initiative of Colorado, JScreen, the Cooperative Agreement 24-0061 of the Centers for Disease Control and Prevention, and the Florence and Joseph Appleman Lecture Series whose support made this possible.

As we begin to wrap up, please take a moment to fill out a brief evaluation survey that's being put into the chat. It really does inform our future programming. Also, a reminder that our Tranquil Thursday's yoga webinar series is happening this Thursday, and the registration link for that is going into the chat as well.

Remember that Sharsheret is here for you and your loved ones. We provide emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience. All are completely free and confidential, and our contact information is in the chat box now. We're putting the evaluation link in the chat box one more time.

The program is being recorded and we will be sending out the recording along with a transcript in the next week or so. Thank you all for spending your evening with us and we hope to see you on an upcoming webinar soon.