Generations of Understanding Navigating the Conversation on Inherited Cancer Genes with Loved Ones

National Webinar Transcript

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Presented by:

About Sharsheret

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

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

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

Sharsheret offers the following national programs:

The Link Program

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

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

Education and Outreach Programs

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

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Melissa:

Thank you so much for joining us tonight. We're going to get started in just a couple of minutes. Again, thank you so much for being here. We'll get started in just one minute. Good evening. Thank you so much for joining us this evening for, honestly, an important, and unique conversation. We know that inherited cancer mutations are not just a personal health issue, but a family concern. When someone learns they carry a mutation, the conversation often focuses on next steps in personal health, and risk management. The decision on who to tell, and how to tell is often left to us, and sharing this information is complicated, and particularly difficult when talking to our children about it, knowing we may have passed a mutation onto them. So, this evening we are going to dive into that conversation, and explore ways to make it just a bit easier. But before we begin, I have a few housekeeping items to share.

Melissa:

First, I would love to thank our sponsors AstraZeneca, the Basser Center for BRCA, and the Max and Anna Baran, Ben and Sarah Baran, and Milton Baran Endowment Fund of the Jewish Community Foundation of Los Angeles for their generous support. Tonight's webinar is being recorded, and will be posted on Sharsheret's website along with a transcript for you to use as a resource. Participants' names, and faces of course will not be in the recording. You also have the option to be anonymous this evening. The instructions were just placed in the chat box on how to do that. Additionally, we now have closed captions available. The instructions to activate them are in the chat now. We've received many, many really great questions through the registration process. I am sure additional questions will arise during the presentation. Please use the chat box. We will be monitoring it, and we will address them during the Q&A at the end of today's presentation. As a reminder, Sharsheret has been providing telehealth services to the breast, and ovarian cancer communities for more than 20 years, because cancer is so much more than simply a physical experience.

Melissa:

If you are interested in finding out more about Sharsheret's free, confidential, and personalized services. Please email us, or visit our website at Sharsheret.org. As we move into tonight's presentation, I want to remind you that Sharsheret is a national, not-for-profit cancer support, and education organization, and does not provide any medical advice. The information provided by Sharsheret, and tonight's speakers is not a substitute for medical advice, or treatment for a specific medical condition. You should not use this information to diagnose. As always, seek the advice of your physician, or qualified healthcare provider with any questions you may have. We are so fortunate to have three speakers with us today. Before we begin with our expert tonight on communication, we are incredibly lucky to have with us a different type of expert, someone

who's been through it herself. Andrea, who I'm going to bring on up on the screen. Andrea is a Sharsheret caller who has agreed to share her story tonight so we can all benefit from her experience. Andrea, the floor is yours. You are muted.

Andrea:

There's some noise going on in the background.

Melissa:

You got it.

Andrea:

Okay. Sorry everybody. Okay. This is totally out of my comfort zone speaking on the Zoom meeting, but I feel very passionate about this topic. I'm hoping to help as many people as I can. Since so many people have helped me. A little about my journey, my first cousin, who's like a sister to me who was diagnosed with ovarian cancer two years ago when she was 62, which was shocking. I'm already 58, and we really didn't have a lot of people in our family with cancer, and nobody that we know of had breast, or ovarian cancer until my cousin's diagnosis. And then about four months later, she told us she tested positive for the BRCA1 mutation, which was also shocking. Her brother tested positive as well. My sister ended up testing when she told me in September that she tested positive, I ran out that day to test.

Andrea:

My cousin's twins tested, too. His daughter tested positive but son negative, which gave me some hope. I got the results a few weeks later that I was positive, too. The first thing I thought of, and made me sick inside was knowing my kids had a 50% chance of having this mutation, and how was I ever going to tell them? It was hard telling my husband as well since he's of the mindset of ignorance is bliss. He even asked, "Am I sure I want to get tested?" He was devastated when we found out, but became a great support to me, and started doing lots of research on the internet. Thankfully, he found the organizations Sharsheret and FORCE. We set up appointments, and spoke with counselors, and read lots of material regarding the mutation, and next steps, and also had to discuss this all with my kids who were 18, and 22 at the time.

Andrea:

Peggy shared lots of information, and an interactive video. I Googled a ton as well, and read lots of people's stories. We looked at this when we found out we were positive as a blessing, and a curse, but really thinking the whole time knowledge is power. We have the power to do something, and do whatever we can to do to avoid getting cancer. All along it weighed heavily on me every day thinking about telling my kids how to tell them, and burdening them with the knowledge of what is happening to me, and the risk that they can have this mutation as well. I felt bad that by telling them it was relieving me of the burden, but then passing the burden of the knowledge onto them. My sister and I decided to both have hysterectomies actually a year ago this week. My kids are very close to my sister, so I had to tell them we were both having surgery.

Andrea:

I actually had a cyst on my uterus, and my sister had a polyp, so we told the kids that we decided to both have the surgery because of our cousin's diagnosis. This was all the truth, but we didn't mention the BRCA mutation, we just weren't ready to burden them with the information just yet. After speaking with doctors, and counselors, my husband, and I realized our kids really didn't need to know until they're around 25 since MRIs, and screenings aren't really done until then, and have decided to go the surgery route, they didn't have to have any surgery until 25, or older. The problem was my sister, and I decided to have the mastectomies next, and if we didn't

share the BRCA info, they would think we had breast cancer. After many consultations with different surgeons, and speaking with different genetic counselors, I had a plan of action, and felt like I was in a good place, so I felt good about telling them.

Andrea:

I told my son first. He was visiting, so it was good that I could tell him in person. I wanted to tell him without his girlfriend present as I thought it is his story to tell. He was okay not telling my daughter at the same time, and agreed better to tell her over the summer so we'd have some time together before she had to go back to college. He was glad I told him, although he felt bad, that I was so nervous telling him, and that I had to go through the surgery. He was very supportive, and told me I'm doing the right thing. He said once he gets settled in New York, since he, and his girlfriend were moving there soon he'd find a doctor, get tested, and do his own research. So, in the middle of the summer when I thought it was a good time, and I felt at peace, I told my daughter about BRCA, and that we now know why my cousin was diagnosed with ovarian cancer.

Andrea:

I also stayed positive, and calm while telling her. She had also babysat for two boys in which the mom had the BRCA2 mutations, so she was somewhat familiar with it. I told her I decided I would have surgery in New York around the same time as my sister using the same surgeons, and helping each other through it. My daughter asked if it means she has the mutation too, and will she have to have the surgeries as well. I told her she had a 50% chance of not having it, and the surgeries will be up to her. She can choose to have screenings every six months instead. I ended up telling her about a family friend who has the BRCA2 mutation who had a hysterectomy, but decided to hold off from having the mastectomy since her daughters are younger, and still in the house, and figured she'd wait, and do the screenings every six months for the time being. She then decided to have the mastectomy, but the last scan showed she already had breast cancer.

Andrea:

Thankfully only stage like zero to one, so caught very, very early. My daughter became very upset, but realized this was the reason why I decided to have the surgery. My cousin's daughter who tested positive had a double mastectomy at 28, and is doing great. My sister, and I use the same surgeon as her, telling my daughter this was helpful since she'll have her support if needed. Both my daughter, and son, I think, are doing well with the news, although I'm sure they think about it, and wonder what their journey will be like, and praying they're negative, but whatever will be, they will get through it. They'll have each other for support as well as my husband, and I, and many family members. They also see how well my sister, cousin, and I are doing, which I'm sure gives them hope as well. When I went for my follow-up appointment with the oncologist surgeon, I was asking her about my kids, and her response was let them live their life, and not test till 25. I told my kids this. Some like to know right away though.

Andrea:

The problem is depending on how old you are, my daughter is almost 20, so if she tests positive now, she'll have over five years of anxiety waiting to do tests, and stressing whether to have surgery, or not. Of course, it would be great to test now, and be negative, but that's the unknown. For now, we can hope she's negative for five years, and my son for two, and a half. I did tell them that their journey will be different from mine since there's so much technology, and research being done. If they are positive, they won't have to share with their children, and have the fear of passing this on to them since the mutation can stop with them, they can utilize in vitro fertilization to select embryos without the inherited gene mutation. I've also told them that they're working on a vaccine for the BRCA mutations.

Andrea:

The vaccine is currently being tested in individuals who have BRCA mutations who have never had cancer. This is their journey though, so they will make their own decisions, but I'll be there every step of the way to be supportive, and help in any way I can. Thank you, and I'll stay to the end if anybody has questions, and if anybody has any questions, and one-on-one. Peggy has my contact information. Oh, I can't hear.

Melissa:

That was me. That's a very generous offer, and thank you so much for sharing your story. We really appreciate it

Andrea:

...getting a little emotional.

Melissa:

I know, it's an emotional topic, but actually, you have a hopeful story. You, and your children seem to have handled it very well, so thank you. And if anybody has any questions specifically for Andrea, we will have the Q&A at the end. Thank you very much. Okay. Our primary speaker this evening is Dr. Marleah Dean Kruzel. She is an associate professor at the University of South Florida in the Department of Communications. Her primary research intersects health, interpersonal, and applied communication emphasizing how communication can improve health outcomes among different healthcare stakeholders. Informed by a problem centered approach, Dr. Dean Kruzel examines how communication is effective for decision-making, uncertainty management, and promoting preventative behaviors. Her publications can be found in journal outlets such as Health Communication, Journal of Health communication, Academic Medicine, Journal of Genetic Counseling, Social Science and Medicine, and many more.

Melissa:

In addition to her research, she loves to teach, two of her favorite classes are patient provider communication, and health communication. Our second speaker tonight is our own Peggy Cottrell. Many of you may already know Peggy who serves as Sharsheret's genetic program manager. She's a graduate of Sarah Lawrence College Master of Science and Genetic Counseling Program. At Sharsheret, Peggy consults with women, and families, and answers individual questions about their family history, hereditary cancer mutations, personal risk, and contributes to the development, and implementation of Sharsheret's hereditary cancer resources, and programs. So, tonight we're going to welcome to the screen Dr. Dean Kruzel first, I am going to get her up here. Welcome. And I am going to begin by sharing your slides. Okay.

Dr. Marleah Dean Kruzel:

Great. Thank you so much for that introduction. It's a pleasure to be with all of you tonight. But first, I wanted to thank Andrea. Andrea, thank you so much for starting off this conversation. It was an honor to listen to your story, and I'm sure many of us on this webinar can relate to different components of it, so I appreciate that. As was shared, what we're going to be focusing on tonight is communicating with family members, and particularly children about inherited cancer risks. Next slide. But before I begin, I wanted to note that I do not have any disclosures, and also acknowledge some funding for portions of this presentation, which are supported by the Centers for Disease Control and Prevention as well as the National Cancer Institute. Next slide. So, like Andrea, let me tell you a little bit about myself, personally. When I was eight years old, my mother found a lump.

Dr. Marleah Dean Kruzel:

It was a tiny lump, barely even noticeable, but I watched her undergo breast surgery on her left breast, chemotherapy, radiation, and then later a prophylactic mastectomy on her right breast followed by construction. In addition to my mother who's in the middle of this photo, my mom's younger sister on the far right was diagnosed with breast cancer two years later, and soon after that, digging through our family tree, we learned that my great-grandmother died of breast cancer at age 35, my current age right now. Years later, after my mother's, and my aunt's diagnosis, we learned the reasons for these diagnoses, an inherited mutation in the BRCA2 gene, which as you can see from the graph, greatly increases our lifetime risk for developing hereditary breast, and ovarian cancer. And since then, my aunt on the left, on the other side, and I underwent genetic counseling, and testing.

Dr. Marleah Dean Kruzel:

And so we are now all positive. So, to honor their health stories, and help me cope with my own, I now wield my role as a BRCA2 previvor, someone who has an inherited gene mutation, but who has not been diagnosed with cancer, a health communication researcher as you heard, but also an advocate to empower patients like you, and me, and then teach patient-centered communication skills to clinicians. So, I'm going to do two main things today. I'm going to briefly summarize some research on communicating with family members, particularly children, which really echoes a lot of what Andrea talked about today. And then I'm going to offer some specific communication skills, and tips for having these difficult conversations with family members. Again, a lot of what you'll see echoing from Andrea's story. Next slide.

Dr. Marleah Dean Kruzel:

So, my early childhood experiences really sparked this interest of mine into the pursuit of health communication. So, this idea, using communication strategies to understand, and improve patients, their family members, and clinicians experiences, decisions as well as health outcomes. But as I've worked with a lot of these different stakeholders over the years, I've realized that we often use the word communication. We take that for granted. So, to be clear, for the purpose of this presentation, and how I see it as a researcher as well as a patient, I wanted to define it for you. So, communication for me is transactional. It is iterative. That means that it is between individuals, and it is through communication between verbal, and nonverbal messages that we co-construct these conversations, and ultimately our relationship. So, what do I mean by that? What's essential here? Communication is not linear, meaning that one person talks, they stop, and then another person receives the information, processes it, what is shared, and then responds back. It's done simultaneously.

Dr. Marleah Dean Kruzel:

And additionally, as you see here in this figure is that each interacting, or in our case for this conversation, parent, and child, we all have our own knowledge, attitudes, values, beliefs, behaviors, preferences, experiences. And those things influence our communication, verbal, and nonverbal messages, and that ultimately impacts our relationship with each other. Next slide. So, researchers all over the world, including myself, have been trying to assist family members in disclosing, or sharing genetic test results, and communicating genetic risk information broadly. Now, overall, this research has found how families communicate about hereditary cancer risk really varies based in a variety of different individual factors that you see listed here. I just want to highlight a couple. The relationship type, so parent, child, cousin to cousin, mother to daughter, the physical, or emotional closeness that we might feel with our family members, the person's perceptions of whether, or not they think their family members may want to know, or should know about their own inherited gene mutation. And then also their personal emotions, right? Anger, or guilt, or fear. And then we also have some additional factors at the more healthcare provider system level.

Dr. Marleah Dean Kruzel:

So, it could be our healthcare provider's knowledge, or support, the amount of support we feel from our family members, and friends in terms of sharing genetic risk information, and then also available tools, and resources. Next slide. So, to elucidate these factors a little bit more, I thought I would share some hot off the press, almost some preliminary results of our recent study, my colleagues, and I are finishing up right now, and we'll be submitting to publication. So, you're the first to see this. This was a collaborative effort with some colleagues in Ireland, and Spain, and specifically we conducted what we call a scoping review. And this just basically means that we looked at a ton of research across a variety of different journals, across a variety of different disciplines, and we were trying to understand, and summarize who, when, how, and why parents disclose their BRCA genetic test results specifically to their children. So, after scouring the internet, we ended up identifying only 11 research studies that fit our criteria of trying to answer those questions of who, when, how, and why.

Dr. Marleah Dean Kruzel:

As you can see here in the slide, it was almost within a 20 year span, and most of those studies were conducted in the US. So, now I'd like to share with you who discloses when, and how parents disclose, and why parents disclose, and hopefully it will help you in your own decision making, and sharing risk information. Next slide. So, really quick for terms, you'll see A GTR on a lot of these next slides. I'm referring to genetic test results, it just shortens it a little bit. All right, so first off, we found that usually female BRCA carriers are the ones who disclose the genetic test results mostly to their daughters, and to older children. And that makes sense, because another finding was that parents tend to disclose to children based on their assessment of their maturity. And then third, parents usually disclose their genetic test results right after receiving their results.

Dr. Marleah Dean Kruzel:

And then those who did decide to delay did so because they were either worried about their children's emotional reactions, or it was because of a cancer diagnosis, or in the case of Andrea's story, a surgery initiated that disclosure. Next slide. There were also things that facilitated, or motivated parents' decision to disclose their genetic test results with children. So, some of the studies talked about families who were strong, supportive families who engaged in what these studies called open communication that made it easier for parents to disclose those genetic test results. Additionally, parents reported feeling responsible to share the information with their children. Now, in terms of how, and where, the studies talked about how parents planned ahead before having these conversations, and we're really careful not to try, and overwhelm their children with too much information. And then finally, parents usually disclosed privately in person, and in face-to-face. And again, we see that in Andrea's story as well. Next slide.

Dr. Marleah Dean Kruzel:

We also found that parents, and children's reactions varied after having this conversation. After disclosing some parents' studies reported they felt guilty, a little bit of regret, they were anxious, but then others were relieved, or satisfied with the encounter. Some of the children in the studies had positive feelings about learning their genetic test results from their parents, and then others did react with fear, and concern. And then finally we had a little bit of variety in terms of some children felt a stronger connection to their parents. While others reported that the family relationships were really unchanged after sharing that genetic test result. Next slide. So, last, we did not identify any research studies that involved healthcare providers, or clinicians. And I think this is telling, and I will say also from my perspective, problematic. It's problematic because it

demonstrates that we are having to decide to disclose, and prepare for these difficult conversations often without help, as was said earlier.

Dr. Marleah Dean Kruzel:

In the studies that we reviewed, we found parents really wanted, and desired more guidance from their healthcare providers regarding how to disclose genetic test results apart from just a simple family sharing letter. And furthermore, parents shared that it would be really helpful if providers would discuss some pros, and cons for sharing that information, and even disclosing to the family members themselves to take that burden off them. Next slide. So, based on this research, and others, I now want to offer some specific communication tips, and advice for having these difficult conversations with family members, and then I'll focus specifically on children. So, the first communication tip is to prepare to talk. In a collaboration I have called Project Impact, this is with Dr. Tuya Pal at Vanderbilt Cancer Center, and Dr. Debbie Cragan, and myself at USF, and some others. We've created a planning guide for sharing. Now, while we may be nervous about sharing, or not know what to share, research has found, and I hope this is encouraging, that most family members want the information to be shared with them.

Dr. Marleah Dean Kruzel:

And most people decide to share that genetic risk information. As such, it can be helpful to think through which family members you should share with, how you should share with them, when to share with them, and keeping in line with that model I showed you at the beginning when to follow up, because it's not a one, and done conversation. So, to help you have these difficult conversations, set a time, and a day to share. Find contact information for family members, especially, when you don't speak to them regularly. If it's too difficult, maybe invite a family member to share on your behalf, decide who to tell each person in the family, and then also, again, who to follow up with them. And lastly, you can send family members a letter, or an email in addition to any verbal communication if that's not yet possible. Next slide. Second. The next tip is to think through, and practice. I talk about this all the time when teaching public speaking practice having the conversation, because it helps us give confidence, and assist in this conversation, research has found that many people feel unprepared to share information.

Dr. Marleah Dean Kruzel:

And so for our intervention with impact, we created conversational scripts as starting points, and you can do the same thing. I would encourage you to focus on what's most important for the person you are talking to first, and tailor that information to them. So, this means that perhaps a conversation you might have with your brother might look a little bit different than you might have with your aunt, or your son. So, for example, you could start off by simply saying, so I found out recently I have an inherited gene mutation. This raises my risk, and increases my chance of getting cancer. Because of this mutation, it can be passed down in families, and so you might be at risk, too. Genetic testing can tell you if you have an inherited gene mutation, or not. I'm happy to answer any questions that you might have now, or in the future, and I can even help you find a genetic counselor should you decide to get tested. Again, a lot of this language we heard from Andrea's story, which is great. Next slide.

Dr. Marleah Dean Kruzel:

Finally, research has also found that one barrier to sharing genetic risk information is perceptions. Perceptions on how their family members might react. So, as you can see here, we created a resource of project impact, which really helps family members try to anticipate their family members, and how they might react to the conversation, and then provide some suggestions for responses. As you saw from the scoping review results I shared briefly, family members may react positively, they might be unsure, or maybe not even show interest, or concern, and they can also react negatively, or even pushback. So, for example, if you're

concerned that a family member might be upset that you shared your BRCA genetic test results with them, you can think through some possible responses to have them ready to go. Maybe something like, "I can understand why this information made you feel scared, or angry. We'll figure out some next steps together." Or, "I'm sorry, this is a lot to take in. I'm here for you, but I can also give you some space, and I can follow up in a few days."

Dr. Marleah Dean Kruzel:

But it's perhaps with our children, and I have to myself that we are most concerned about how they will react, and how they will be affected. And we see this in Andrea's story, too. So, I'm going to conclude by sharing with you some guiding strategies for communicating specifically with children. Next slide. So, as you may know, BRCA genetic testing for minors is not recommended until adulthood when cancer risk management practices can actually be utilized. Now, at the same time, many parents consider, and do end up disclosing their genetic test results at multiple stages of their healthcare journey. Again, especially when maybe a family member is diagnosed with cancer, as I discussed earlier, parents who decide not to disclose their genetic test results right away to their children usually do so because they have concerns about a child's fear of getting cancer, or maybe anxiety about their parents' health, and how that genetic testing information is going to impact their health.

Dr. Marleah Dean Kruzel:

Yet you might have children like I was at eight years old who wanted to be involved as much as her parents possibly would let her as a way to cope with everything. So, if that's the case, here are some guiding recommendations again, based on research. Number one, when planning, specifically, you want to consider the timing, and plan the location. So, for example, you might want to talk to your children when they are not tired, or scared, especially if they're, again, minors. Also, figure out where it's the best place to share that information with the child. Is it in public? Is it in a comfortable private space? Number two, use age appropriate communication, and plain language terms. So, for example, a teenager will likely understand a little bit about what it means to have a genetic mutation given their science in school, and how that can be passed down from a parent. So, be prepared to answer any questions that they might have, or be prepared to say, "That's a really great question. I don't know that. Let's figure it out together. We'll do some research."

Dr. Marleah Dean Kruzel:

And then number three, tailor your conversation to your child's level of development, cognitive ability, and maturity, emotional, and behavioral maturity. And I think Peggy probably provides some great resources, and expertise in this space. As one example here, one book that might be a helpful resource that I have found helpful is a book called Moms Genes. It's targeted for younger children, which is a story that teaches children about their family health history. So, overall, there's no doubt that these conversations can be challenging, but with preparation, reflection, and practice, hopefully you'll feel a little bit more comfortable, and confident. Next slide. So, I also wanted to share some specific communication advice that I have received from patients that I've conducted research with, patients with inherited cancer risks when they're having these difficult conversations. So, the first advice from other patients is to engage in two-way dialogue. Sharing genetic test results is not a one, and done conversation. It requires multiple conversations over time. This is especially relevant for children, right?

Dr. Marleah Dean Kruzel:

Your children will likely have questions as they process things no matter their stage of life. And sharing information in stages based on age appropriate information will help reduce information overload, and potentially emotional reactions. In turn, though, the second piece of advice is to know that these conversations, and the decision to have these conversations can be really

emotional. Having this expectation for yourself, but also anticipating that the children, or family members might be emotional too, will help you in that moment. But also, again, practicing what you're going to say, writing down some notes if you don't think well on your feet will also help you manage those emotions in the moment. And then lastly, be flexible. It's okay to change your mind about sharing. You might plan to share. You might get up the nerve, you might set up everything in the way that you want, and then you end up not being able to share, and that's okay. So, give yourself some grace, and then try again in the future. Next slide.

Dr. Marleah Dean Kruzel:

Finally, I wanted to share some few additional great resources that might be helpful for you as you prepare, and plan, and reflect, and ultimately have these difficult conversations. Number one is KinTalk. This is a resource that guides you through a conversation with relatives about an inherited gene mutation in the family. The CDC also just recently launched a new app which is designed to help you collect your family's history of cancer, and specifically risks for hereditary cancers. FORCE as was mentioned earlier in Andrea's story, there is a brochure called The Genes Between Us, and this is a step by step guide for talking with your relatives about medical information, and ultimately sharing that information with them. And then of course, we have Sharsheret, they have an excellent resource for how to tell your children about an inherited mutation as well. Next slide.

Dr. Marleah Dean Kruzel:

So, as I conclude, I thought I would share some final words, final wise, honest words from my aunt, and my mother based on some conversations that we've had, which I hope reiterate a lot of the research, and communication tips I've shared with you today. So, here's my aunt. It's hard for me to separate the experience of breast cancer with learning about our BRCA2 gene mutation. Both happened in my thirties with three children. Finding out I had breast cancer was shocking. Finding out I was BRCA positive was not. As soon as I knew I had the gene mutation, I shared it with my three children. Despite their age, I didn't see the reason to withhold the information, but I also didn't see it as something traumatic. I think they just grew up knowing that this was something they needed to be aware of with their bodies, but certainly not something that should dominate their life. On, and off, over the years, we've talked about it as a part of a normal part of who we are.

Dr. Marleah Dean Kruzel:

My daughters have always wanted to have genetic testing, and are open to prophylactic surgery, but they don't usually talk about it with great anxiety. They know it didn't derail my life, and I think they take the same approach. Next slide. My mother. I am a firm believer in the beginning of sharing a more upbeat perspective when disclosing a positive BRCA status, or any cancer diagnosis. If needed, later one can deal with the more serious issues. Marleah, and I can't remember when, or how we disclosed my BRCA status to her. I believe that is a good sign. Early on, and still occasionally I have felt, and feel guilty about passing on the BRCA gene mutation to Marleah. People can say, "Oh, you didn't know", but still, it doesn't make the ache go away. Yet overall, my best advice is what I told Marleah so many years ago, which has become her mantra. You make the best decision you can with the information you have at that time.

Dr. Marleah Dean Kruzel:

In short, I hope that the research I've shared with you, and the communication strategies, and specific resources will help you on your own journey. And I hope these final words are encouraging. So, may my mother's wise words comfort, and empower you, and I as they have me. Thank you. Oh, and there's a collaboration slide. Sorry, Melissa, if you don't mind holding

that up for my fabulous colleagues, too. Yeah, next slide. Perfect. Thank you so much. I just wanted to call them out because this is the work of many, not just one. Thank you.

Melissa:

Amazing. Thank you so much for that, such clear, practical advice. And of course, Dr. Dean Kruzel is going to stay for questions at the end. Now, I am going to welcome to the screen, like I said, somebody that many of you already know, Peggy Cottrell, who will be talking a little bit about the same topic, but also a couple of updates in the field of hereditary cancer mutations. Thank you.

Peggy Cottrell:

Thank you, Melissa, for that nice introduction. So, thank you, Marleah, that was a great talk. And I know I've spoken to so many women over the years about this topic, and I know this is one of the hardest things you might think many women would say, "Well, isn't the hardest thing going through the surgery?" But I think that for many, many women, the hardest thing is having to talk about this with their kids to have to imagine the difficulty that they will go through. And so I want you to know that we're here for you at Sharsheret, and while I can't do this job for you, I can certainly give you a lot of information, a lot of resources that can help you do this in the easiest way possible. And I think that, for many people, the buildup, and the nervousness about having to say these things is usually a lot more difficult than the actual conversation.

Peggy Cottrell:

And I think it's important to remember that your job is... When our kids are young, of course we're always telling them what to do. It's our job often as mothers, but our kids get to a certain age, and it becomes not really our job to tell them what to do in quite the same way. So, with these inherited mutations, it's really important to remember that when you're talking about it with anyone in your family, your job is really to let your family member, a sibling, a parent, a child, let them know about your result, let them know the decisions you made, and let them know you're there to help them make the right decisions for themselves. But we're not there once our kids are adults to tell them what to do in the same kind of a way. So, if you have questions about this aspect, don't hesitate to be in touch with us at Sharsheret, and I can help walk you through this process. We also have peer supporters at Sharsheret, so we can hook you up with somebody who has been down this road, and has talked to their own children.

Peggy Cottrell:

So, I'm going to share my screen, and I want to talk a little bit about genetic updates. Okay, so I want to talk a little bit about pancreatic cancer screening. And that's because and this is off-topic totally from talking to your children, but it's something important, and new that's really changed within the last year, or two in the BRCA space, and that is that studies have really been coming through now that are showing that screening for pancreatic cancer can be effective at saving lives. So, people can find pancreatic cancer at an early enough stage, and it can be treated, and they can go on to survive, and live many years afterwards. And that's not something that we were originally sure we were able to do. And so what kind of screening is involved, and who is eligible for that kind of screening? So, first of all, people with an inherited mutation, and you see a long list of mutations here. I'm not going to read them. BRCA1, and BRCA2 are in the group as well as other inherited mutations.

Peggy Cottrell:

The age that you start screening is going to depend on the specific mutation. And if you look more closely at the National Comprehensive Cancer Network guidelines that I've posted on this slide, you can see that the timing is variable, but I'll mention BRCA1, and two, because I think most people who are tuning in are carriers for those mutations. And screening is considered

best to begin with these mutations around age 50. Some experts recommend that people who are eligible for the screening not only have a mutation but have a family history as well. But other experts don't feel that that's necessary. So, what is the screening? It's two different tests. Generally, it's thought that each test should be done annually, but perhaps tests done six months apart from each other. The first is an MRCP, which is a specialized MRI that looks at the pancreas, and its associated ducts. And so I think from the point of view of the person, it's like a regular MRI, there would be contrast.

Peggy Cottrell:

The second test is called an EUS, which is an endoscopic ultrasound. And what that means is you have an endoscopy, which is where you are sedated, they put a tube down into your stomach, but instead of that tube, just having a camera at the end so that they can look around, it has an ultrasound probe. And so your gastroenterologist is able to take an ultrasound picture of the pancreas from the wall of the stomach. And these two tests have been able to identify the very earliest stages of pancreatic cancer lesions, and make a difference in survival, which is an amazing accomplishment. So, if you have questions about whether you might be eligible for this type of screening, you may be eligible just based on family history.

Peggy Cottrell:

If it turns out you have multiple more than one family member that's had pancreatic cancer but no identified genetic mutation, you may still be eligible. There are studies looking at this. It's really important when you're doing this kind of screening to do it with an experienced medical team. So, I'm going to stop sharing, and I think I'd like to at this point, I know we have a lot of really great questions, and let's move on to the question and answer portion of our evening.

Melissa:

Okay, thank you. Thank you so much. I'm going to bring at spotlight as I'm adding spotlight, Peggy, let me ask you to clarify why, I'm sure that everybody who's on the webinar knows this, but let's get you to clarify why you were talking about pancreatic cancer, because we spoke a lot about breast, and ovarian tonight, but can you talk about the other risks involved with carrying some of these mutations?

Peggy Cottrell:

Very good point. So, those with a BRCA one mutation probably have, instead of about the average person, about a 1% chance to develop pancreatic cancer, and it can happen to anybody. With a BRCA1 mutation. That risk is two, or three times higher, so about two, or 3%. And with a BRCA2 mutation, maybe more like four to 6%, that risk comes later. Most people, it's not that people do develop pancreatic cancer before 50, but it's pretty rare. And so the time to start screening is a little bit later. Again, most people with a BRCA1, or BRCA2 mutation are not going to get pancreatic cancer. It's still relatively unlikely but more possible than the average person, and that's why this kind of screening is available in these situations.

Melissa:

Thank you for that. And what are the other cancers that are associated with a heightened risk with these mutations?

Peggy Cottrell:

So, besides breast cancer, they're also a risk for male breast cancer, ovarian cancer, pancreatic cancer, and in men prostate cancer, and possibly a risk for melanoma with BRCA2.

Melissa:

Thank you. We tend to think about even those who talk about it a lot as a breast, and ovarian cancer mutation, but it is much more than that, so I appreciate that. Okay, so let's get started

with some questions. So, there were several questions about the right age to tell your child, and I know Dr. Dean Kruzel, you said that action preventative screening, or screenings, and any preventative action don't usually start till 25, and that everybody's a little different. But in general, what do you tell people when they're looking for that information?

Dr. Marleah Dean Kruzel:

Yeah, I know. As a patient the standard answer of it depends, is frustrating. So, I appreciate that question. But I am going to kind of sit in the uncertainty there a little bit, and say that it really does kind of depend on your children, and you know your children best. You know how they react. You know if they tend to be a little bit more anxious. You know if they have something big in their life, they're competing in sports, or they're in drama so they can't focus on something, and then later in adulthood, Andrea mentioned about going off to college, and moving to New York, so I hesitate to give a right age, because it really depends on the study.

Melissa:

That's fair. So, a question just popped up in the chat that I thought was interesting. Is there any information, any studies that talk about women talking to daughters, men talking to sons, or switching that up? Is it the person who carries the mutation who should be talking to the child no matter the child's gender?

Dr. Marleah Dean Kruzel:

Yeah, that's a really great question. I can tell you in terms of the scoping review that we did, which is looking at lots, and I think we ended up reading about 75 articles, and then ended up the 11 only related to our interests, but we did find that usually it's the female carriers who are disclosing more, and it is also the females in a relationship who are disclosing when they are the non-carriers as well. At least that's what has been... Which is somewhat not surprising given broader literature that women tend to be the gatekeepers, females tend to be the gatekeepers of health, and kind of navigate that space. So, that doesn't mean that fathers, dads, can't be involved, I think, and I think that does happen. I just saw a great webinar by the Basser Center for BRCA, and it was talking about men, and their family experience, and disclosing that information, and kind of sharing that within the family. So, I think it is done, but in the research we do see it tends to be females.

Melissa:

Okay. But no problem if it's not the female?

Dr. Marleah Dean Kruzel:

No, no. Again, I think it depends on your children. If it makes sense to talk father to son, mother to daughter for your family, or if the mutation is coming from the dad's side, then maybe the best person is for him to disclose. And I do just some research with men with BRCA, and we've created some interventions to help them practice, and talk, and have what can be difficult conversations. So, yes, definitely we encourage that, but again, kind of go back to you know what's best.

Melissa:

Okay. No, that's fair. That's fair. We got a couple of questions about how a parent can deal with their anxiety when a child chooses not to be tested, whether they're disinterested, or they don't want to be tested because of their level of medical anxiety, or whatever that is. So, can you talk a little bit about that?

Dr. Marleah Dean Kruzel:

Yeah, no, that's a great concern, and I can understand it from a personal side, as well as the research side. We know from the literature that it is common, and for parents to have those

feelings of guilt. You saw that in my mother's story. We talk about that all the time. And then of course, anxiety, too, in terms of having those conversations. In terms of emotional distress, I would say if it is kind of peaking for you, having the good support system, whether that is having that conversation of disclosure with a spouse, or a family member, or something like that to help facilitate that. In terms of deciding whether, or not to get genetic testing, or even, let's say your children get genetic testing, and then they start experiencing scanxiety, which is very common in the previvor population, and happens, at that point, it might be helpful to have psychosocial resources like a social worker, or a psychologist, maybe even a psychiatrist who you might draw on, but leaning into those feelings, I think, and acknowledging those feelings.

Dr. Marleah Dean Kruzel:

And then as the scoping review talked about, or identified this idea of coming from a strong supportive family that has open communication, families that are willing to talk about health. My family was certainly one of those where we talked about a lot of things, and I think we kind of had to given the situation of a young breast cancer diagnosis, but that really enabled us to have frank conversations with each other where maybe, in full disclosure, my parents, for example, are ready for me to have a prophylactic bilateral mastectomy. I'm done with family planning, and NCCN guidelines say that that is a good option for me, but I'm not ready yet. So, you kind of have to negotiate these emotions, and decisions together. What I think is so valuable is if everybody's on the same page no matter what you decide, I'm on your side, I'm in your corner, I tell that to my son. I'm always in your corner, right? So, sorry, I'll stop talking.

Melissa:

No, no, that was a great way to end that answer. That's really important. We have a lot more questions. I'm going to try, and hone in on the ones that are about communication, specifically.

Dr. Marleah Dean Kruzel:

Okay.

Melissa:

This one's a little different, but I think you might have a really insightful answer. So, someone shares that they've experienced cancer already, and it was very difficult for their children, and they've just been diagnosed with a second cancer, a different cancer. How can they talk to their children in the least stressful, or harmful way?

Dr. Marleah Dean Kruzel:

Yeah, yeah. That is a hard situation to be in. Well, I would say trying to find a way in which to reflect on, and anticipate how they might react is a good first step, right? Thinking about, and practicing responses for sharing that information. I also think that, and again, based on research, we know that even though it might be difficult to have these conversations, oftentimes people want the information, even though it might be hard to hear, there have been a few studies that when information was kept from children, that can cause problems as well in terms of an open, trustworthy relationship, and how that could impact it. So, even though it might be a difficult conversation to have, I guess the way that I see it is to have that conversation, maybe break it down in terms of information. A lot of the studies have found to do it privately in person, face to face, but that doesn't necessarily mean that all children will react that way.

Dr. Marleah Dean Kruzel:

We know that for generations right now, maybe a text is actually better, or a Facebook message might be better, because it gives them some space to process their emotions. And then following up, I think the follow-up is so important with any of these conversations is that it's not just I share my genetic test results with you, and that's it. It is, I'm going to be there for you in this process. We're going to work through this together, whether it's a cancer diagnosis, or

sharing genetic test results, I can go deeper if you'd like, but I'm trying to be succinct with our time here.

Melissa:

We don't have a lot time, but since you were so honest about your own situation, I'll take a second to be honest about mine, and hope that it will help with this person who asked this question as a two time, two different cancer survivor, I was able to share with my children, "Look, I'm here. I did it once. We'll do it again." It's very comforting to know we faced it one time, and we'll face it again, and positive outcomes are possible. So, [inaudible 00:57:00] go ahead. No, go ahead.

Dr. Marleah Dean Kruzel:

Go ahead. No, I was just going to say, I think my mother, who is a 25 year survivor would say the same thing in terms of having that upbeat perspective, right? So, yeah, thank you for sharing.

Melissa:

Yeah, so I wish we had time for more questions. I will say that there were some questions that we didn't get to because they were genetics focused, but not necessarily communication focused. We're going to have a follow-up email, and it will give you an opportunity to reach out to Peggy who can answer those genetic questions for you. And there's even an opportunity to request that Peggy reach out to you on the evaluation, which I am going to ask my colleague, Erin, right there to put in the chat box, and you can click on that, and still listen to the last three minutes of the webinar. So, I want to thank Dr. Marleah Dean Kruzel, and of course our beloved Peggy Cottrell, and absolutely Andrea, for sharing your story. I learned so much tonight, and I hope you all feel the same way. I want to remind you that Sharsheret has some wonderful educational resources available to you.

Melissa:

Of particular interest, of course, is I guess you can't really see it, but it says, Your Jewish Genes, which discusses BRCA, and other hereditary cancer mutations, and honestly is appropriate for anyone who has a mutation, or is concerned about their risk. Then the second one was on the slides, which is, How Do I Tell My Children About My Cancer Gene? This speaks more about what we spoke about tonight. I will repeat what Peggy often says, "There's no secret in here." It's a difficult conversation, but this helps make a difficult conversation a little bit less difficult. You have the opportunity to either download these resources, or order print copies, and we'll give you that option through, again, a follow-up e-blast, which you will receive later this week. Please take a moment to fill out that evaluation. Erin, if you could post that one more time, I'd be grateful.

Melissa:

Once again, thank you to AstraZeneca, to the Basser Center for BRCA, to the Max and Anna Baran, Ben and Sarah Baran, and Milton Baran Endowment Fund of the Jewish Community Foundation of Los Angeles for their support of tonight's program. And please remember, that Sharsheret is here for you, and your loved ones. Sharsheret provides emotional support, mental health counseling, genetics information, and all sorts of other programs designed to help you navigate through a cancer experience before, during, and after. All are free, and completely confidential. And you can reach us at the email address in the chat box, clinicalstaff@Sharsheret.org, or you'll be able to request some contact again through the evaluation, or through the follow-up email. Thank you to all who joined us tonight. Thank you again to our amazing speakers. Have a wonderful evening, and good night.