

Treating the Non-Medical Side Effects of Cancer

National Webinar Transcript

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Presented by:



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Treating the Non-Medical Side Effects of Cancer

Melissa:

Sharsheret's website, along with a transcript for you to use as a resource. Participants' faces and names, of course, will not be on the recording.

Melissa:

You also have the option to be anonymous this evening. You can turn off your camera and even change the name in your Zoom square. These instructions are in the chat box right now, and that will help you make those changes.

Melissa:

We received a great number of questions through the registration process and questions I'm sure will arise during the presentation itself. Please use the chat box and we will address them during the Q&A at the end of the webinar.

Melissa:

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 a physical experience.

Melissa:

If you're interested in finding out more about Sharsheret's free, confidential, and personalized services, please email us or visit our website at Sharsheret.org.

Melissa:

Before we welcome our experts today, we are so very fortunate to welcome Laura-Lee, who is a Sharsheret program participant, and is willing to share some of her story this evening.

Melissa:

So Laura-Lee, welcome to the webinar.

Laura-Lee:

Thank you. I'm honored to be here and to just share a little bit. I love Sharsheret. The resources and the people that they provide have been amazing.

Laura-Lee:

I benefited from the Best Face Forward, which they introduced me to. It was the simple little things, a cosmetic line called Thrive.

Laura-Lee:

And, Thrive, they look to provide support for women going through breast cancer and so it was a win-win in a lot of ways. Their products are really good.

Laura-Lee:

I'm also enrolled in the nutritional program that they offer. That's not only helped me to better understand how to eat healthier, but the person is also very focused on eating foods that will reduce the risk of cancer as well as recurrence, which is amazing information.

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Laura-Lee:

They also, through their assistance with Sauler Institute, I had the luxury, honestly, of being able to get my eyebrows microbladed because I didn't have any. I lost them during the first part of my chemo.

Laura-Lee:

And as simple as that might sound, you look in the mirror and not that just to find who you are, but you want to feel like you look pretty.

Laura-Lee:

So Sharsheret and the Sauler Institute has helped me to be able to do that. There wasn't anybody who did the tattooing in St. Louis.

Laura-Lee:

So they actually had to find one and they've been able to secure a tattoo artist that not only does the microblading, but they also do areola tattooing for women who need that. So, it's just amazing what they offer.

Laura-Lee:

I also had the luxury of working with Charna Goldsmith and she provided me with this lovely wig. So again, I'm not defined by my appearance, but it's nice to be able to look in the mirror and see the person that I was in some ways before, with eyebrows, with hair that is closer to what it was before chemo and this wig.

Laura-Lee:

I have a little pixie haircut and it's hey, and I'm used to having long auburn hair so this has just given me the ability to feel confident. Thank you.

Melissa:

Laura-Lee, thank you so much for sharing your story. It was so moving and you've made it so clear why we are talking about this tonight.

Melissa:

Because these cosmetic issues, these non-medical side effects, aren't frivolous. They are important to us and our self esteem and the way we define ourselves.

Melissa:

So let's learn some more about this program. As we move into the webinar itself, I just need to remind you that Sharsheret is a national nonprofit cancer support and education program and does not provide any medical advice or do any medical procedures.

Melissa:

So the information provided by Sharsheret is not a substitute for medical advice or treatment for a specific medical condition.

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Melissa:

You should not use this information to diagnose or treat a health problem and as always seek the advice of your physician or qualified health provider with any questions you have regarding your specific medical condition.

Melissa:

Okay. We are so very fortunate to have several amazing speakers here with us today. All experts involved with our BFF 2.0 program.

Melissa:

Our BFF 2.0, otherwise known as Best Face Forward 2.0 program, provide services and subsidies for eligible individuals for non-medical services that are critical to a woman's quality of life and body image. And that are either only partly covered by insurance, if at all.

Melissa:

As you'll hear tonight, Best Face Forward services include financial subsidies for wigs, otherwise known as cranial hair prosthesis, cold caps or scalp cooling treatments and tattooing, three dimensional micro pigmentation of the nipple and areola, and tattooing of eyebrows, as we just learned, microblading.

Melissa:

Additionally, there are complimentary and holistic offerings such as meditation and yoga. Joining us first is Mandy Sauler, founder and owner of the Sauler Institute of Tattooing.

Melissa:

She specializes in micro pigmentation. And medical tattooist Teion Milbourne, otherwise known as T. T is a scalp micropigmentation and scar camouflage specialist. Both have multiple certifications. Welcome to both of you.

Teion Milbourne:

Hello. How are you?

Mandy Sauler:

Thank you guys. Hello. Hi everyone. Thank you for having us. Sharesheret has been an amazing organization to work with throughout the last several years.

Mandy Sauler:

And we've been so happy to work with you guys. You've been nothing but amazing and we hear nothing but great things about you from our clients.

Mandy Sauler:

So I am Mandy Sauler. I am founder of the Sauler Institute. I just want to tell you a little bit more about what we do. We do do the areola nipple tattooing, and that is a process that after reconstruction, you can choose to have nipple reconstruction and we still create the tattooing with that.

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Mandy Sauler:

Or you can decide to do the 3D areola nipple tattooing, where you opt out of the nipple reconstruction and you just create the illusion of a nipple with the areola nipple tattooing.

Mandy Sauler:

So in both cases, we're still doing tattooing for that after the reconstruction. I think this is a huge thing to think about because a lot of people don't know the impact that it makes.

Mandy Sauler:

But just adding a little bit of color there, it really takes away from every other little imperfection. And so many people are very nervous about it and once they get here, they're like, "I don't know why I was so nervous. This is the most amazing thing I ever did."

Mandy Sauler:

So I'm open to any questions about this process. And also we not only do this here, where we're at in several locations, but we do have and found artists all over the United States.

Mandy Sauler:

So just keep in mind that yes, we are local to the east coast, but we have artists all over the United States that we really went through and made sure that they were properly licensed and qualified and will provide great service for anyone that's interested in this service.

Mandy Sauler:

And for eyebrows, we also do that. So microblading, hair stroke, powdered filled brows. This is great for pre or post-op chemotherapy.

Mandy Sauler:

If you're going through chemotherapy or even if just during the process you've lost hair, whether it was even from stress or with age and things like that during this process, it's a great way to enhance that. And we're happy to provide this service.

Mandy Sauler:

We do do other things like eyeliner and lip coloring and things like that too. But sometimes it's just nice to bring yourself to a state of feeling great after you've gone through such a long process and journey.

Mandy Sauler:

So just a little bit about the services that we do and then Teion also does some amazing, amazing services with scar camouflage.

Mandy Sauler:

He can tell you a little bit more about what we do with scars and with after surgery and then also for hair loss and hair fullness and things like that.

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Teion Milbourne:

Okay. Hi everybody. I am an artist here at the Institute. I do scar and SMP. For those who don't know what SMP is, SMP is scalp, all right? Micropigmentation. Okay? I know it's a lot. So let's keep it simple, SMP right?

Teion Milbourne:

So the bottom line of SMP is to create small, tiny hair follicles, all right, with a microneedle on top of the scalp. Space it out. It probably takes me about three sessions and I'll complete the progress.

Teion Milbourne:

But the one thing about scalp is that a lot of people are nervous about it. And I understand it. A lot of people are nervous when it comes to hair loss.

Teion Milbourne:

But I'm going to be honest with you, SMP is great. All of this is just a needle, a microneedle, and the whole agenda is to make sure it looks organic and natural as I possibly can make it. So I believe what? SMP is more for cancer patients with hair loss.

Mandy Sauler:

Yeah. So hair thinning.

Teion Milbourne:

Hair thinning. And brings the hairline back. I can do hair lines. I even work with people who have alopecia. So I work with a lot of clients like that.

Mandy Sauler:

Tell them about the scars.

Teion Milbourne:

And scars? Scars are my favorite thing. Okay. Scar camouflage. Scars... I believe my major job is just to match the ink with the color of your skin tone. All right.

Teion Milbourne:

So around the scar area, let's say you have a scar over here under your nose, you have a scar here. I will blend from here to here and I will match the color of the skin tone over here. It's really simple. It's just the ink and blending to match the skin.

Melissa:

So that sounds like an alternative for some. We hear a lot about people who get tattoos across their chest to hide the scars.

Melissa:

But this is another option if somebody doesn't want a large artistic tattoo, this will just minimize the look of the scar?

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Mandy Sauler:

Correct. So some people think of scar camouflage with tattoos as we're covering a tattoo over the scar, it's more just matching the undertones of your skin and camouflaging the scar with your natural skin tone colors.

Mandy Sauler:

So it's a great way to look at any surgery scars from after breast reconstruction that may be still there or maybe some microneedling to improve the scars and things like that. So it's definitely a great option for that.

Melissa:

Okay. A lot of questions came in, so don't go anywhere because we're going to circle back to you.

Mandy Sauler:

I can go back through and start, yeah.

Melissa:

Yeah, yeah. Okay. So we're going to get to all those questions after we hear from everybody else. Thank you so much for that. Okay.

Melissa:

Next we have with us Bethany Hornthal of Hair to Stay a national nonprofit dedicated to providing access to scalp cooling during chemotherapy. She is the co-founder and executive director.

Melissa:

Bethany, thank you so much for being with us tonight.

Bethany Hornthal:

Well, thank you for having me. I want to echo everything that's been said about Sharsheret as a partner. We couldn't do what we do for the number of individuals that we do it for, which is now approaching 3,600, I think, without quite a bit of help from the generosity of Sharsheret.

Bethany Hornthal:

And I can't believe every time I start to get low in funding and I start to worry that the next people that come, we may have to say, "Well."

Bethany Hornthal:

I make a call, send a list and suddenly another check arrives. So it's like, I don't know, Chanukah or Christmas, but anyway, in January, February, March, et cetera.

Bethany Hornthal:

So having said that, I think that as Laura-Lee really brought home, cancer takes a lot away from an individual. And some of the things that it takes include identity and control and privacy, and a sense of normalcy and a sense of wellbeing.

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Bethany Hornthal:

Those are all things that, in addition to whatever body parts are being eliminated or changed, those are all things subject to loss.

Bethany Hornthal:

And I think what we found is that hair loss is just one of the most devastating side effects of chemotherapy, because cancer will tend to walk into the room before you do if you have lost your hair.

Bethany Hornthal:

You can have a wig and that can definitely help but people who knew you will know that there's something different about you. So you can't really control sometimes who knows if you've lost your hair. Therefore your privacy is affected.

Bethany Hornthal:

And the one statistic that I think really threw me into this work in full force is, and I hope you can hear me, I'm outside because I have four dogs inside. So I'm in the mountains in California and so it's a little windy.

Bethany Hornthal:

I found out in research that somewhere between eight and 12% of women will actually turn down chemo because of fear of hair loss.

Bethany Hornthal:

So that means we've stripped it away from just a vanity question, which it never really was, but now we're talking potentially life and death.

Bethany Hornthal:

So what happened is that I was working with University of California San Francisco as a consultant helping to find funding for clinical trials and was asked by the director to look into this thing called scalp cooling, which to me sounded a bit like a tribal ritual.

Bethany Hornthal:

But I was told, "Hey, this is happening in Europe and women aren't losing their hair during chemotherapy." And one of the patients at UCSF was dumbfounded. She wanted to buy the thing and move it to California and use it. And lo and behold, we had no FDA clearance to use scalp cooling in the United States.

Bethany Hornthal:

So first let me just say, what is scalp cooling and why does it work? And I had to find this out initially as well. So scalp cooling is a treatment methodology that consists of two things that are happening at the same time that protects the hair.

Bethany Hornthal:

When you chill down the scalp by wearing a cap during chemo, you bring this scalp down about 30 degrees and what happens is that the blood vessels in the hair follicle get very cold and they tighten up, they constrict. Called vasoconstriction.

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Bethany Hornthal:

Anytime you get cold, you're like this, well, your cells are like this too. And so by constricting, they're going to allow way less chemo into that follicle. So maybe 20% gets in instead of 100% percent.

Bethany Hornthal:

Secondly, when you chill down a cell, what happens? Cancer chemo is targeting fast growing cells, which is why you lose your hair and you lose your nails and you have problems with mucus membranes. Those are all the fastest growing cells in the body.

Bethany Hornthal:

So it's targeting those because tumors are fast growing cells and it needs to target those. If you chill down the cell, you slow down the metabolism of the cell. It doesn't replicate as frequently, so it's not as vulnerable to the chemo.

Bethany Hornthal:

Okay. So that's scalp cooling. It's started about 30 minutes before chemotherapy. It goes through the chemotherapy session. And then depending upon the approach, 90 minutes afterwards, if you're using what is called automated scalp cooling, which is with a machine.

Bethany Hornthal:

If you're using manual scalp cooling, which is where you have a cap and you are changing it every 30 minutes, you aren't but somebody is there with you, then you might want to keep that cap on for a longer period of time to make sure that the chemo has really left the system.

Bethany Hornthal:

But that's the inside behind the scenes of what's happening with scalp cooling. So we were able to conduct an FDA trial on scalp cooling between 2010, 2015.

Bethany Hornthal:

We had to prove that 50% of the patients, which were women with breast cancer, would maintain at least 50% of their hair following scalp cooling treatment.

Bethany Hornthal:

And we were able to prove that about 69 to 70% of women were able to maintain at least 50% of your hair. If you keep 50% of your hair, few people know that you have been going through chemo and are losing your hair.

Bethany Hornthal:

So what Hair to Stay came to be because insurance was not really interested in how much cancer costs and cancer treatment costs.

Bethany Hornthal:

And we found very early on that they were not going to cover at all scalp cooling originally. So having been involved in trying to bring this technology to the country, it did not feel good to me that a third of the people that would be wanting to use it would not be able to afford it, at least a third.

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Bethany Hornthal:

So we began Hair to Stay in 2016. I have a co-founder Patsy Graham who had breast cancer, had used Penguin Cold Caps, and was so excited about what happened and how she was able to have her hair, that she started working for Penguin Cold Caps.

Bethany Hornthal:

And then I approached her in 2016 when we had FDA clearance and said, "Would you like to take this beyond Texas and into a bigger environment?"

Bethany Hornthal:

So Patsy's retired, so I am still at the helm. And at this point we fund patients in all 50 states, we fund eligible patients and it depends.

Bethany Hornthal:

We have two types of funding. We have a national fund and anybody can be up to three times the federal poverty level. We also have targeted funds, which is what Sharsheret is, which are very generous funds.

Bethany Hornthal:

And we are able to go to a lower eligibility criteria and provide more money. So scalp cooling costs somewhere between 1,200 and \$3,000, depending on how many infusions you might have and we will provide with Sharsheret funding up to \$1,750 for these treatments.

Bethany Hornthal:

So those are the details and I'm certainly open for questions in anywhere else you want me to go Melissa with this or not? And just save you some time. Your call.

Melissa:

I'm watching the questions come in. I've made some notes. So once we get through all of them, we're going to circle back.

Bethany Hornthal:

Okay.

Melissa:

But thank you very much. I'm sure a lot of people really learned a lot there because it's not something that the average person is familiar with.

Melissa:

And speaking of hair, I'd like to share a brief video with you from Charna Goldsmith and CG Wigs, which alongside other services, provides wigs to those facing hair loss from cancer treatment.

Charna Goldsmith:

I'm Charna Goldsmith and I'm the founder of CG Wigs. Sharsheret is a non-for-profit that helps women with ovarian and breast cancer.

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Charna Goldsmith:

Being able to partner with Sharsheret and be able to provide these women with custom human hair wigs has been a life changing experience.

Charna Goldsmith:

But while Sharsheret provides round the clock support and care, my company is able to provide them with getting back to a sense of their self.

Laura Cohen:

The process of losing one's hair is so, so personal and so devastating and having a wig that wasn't just something I ordered off a shelf, it was something that was personally designed custom made for my size and my head and my color choices just made all the difference in helping me to feel some degree of normal again. It was just unbelievable. I really can't even put it into words

Charna Goldsmith:

Today, with technology, we're able to create a custom wig for any woman anywhere across the country. We basically video conference with them, talk to them a little bit about their natural hair, what they're looking to recreate. And once they choose color and send us their measurements is when our creative process begins.

Laura Cohen:

Being able to have a wig custom made and designed from the comfort of my home was such a huge part of what made this so helpful for me.

Charna Goldsmith:

Once the client's reached out to Sharsheret and we've had our first phone conversation with them, I'll explain to them how to measure their head for a wig and then they can go ahead and email us those measurements.

Charna Goldsmith:

Once we receive the measurements, we'll go on to discuss color options and their color needs. Typically, it will take us a couple of phone or video sessions to match them.

Charna Goldsmith:

They also have the option of sending in a hair sample and if they send us in a snippet of their hair before they do their major chop, we're actually able to perfectly color match it with our samples in the shop.

Charna Goldsmith:

Being able to work with women virtually has really been a game changer, which means that you could be across the country having a wig made for you.

Charna Goldsmith:

It gets shipped to you priority mail and once you receive it, you can go ahead and have it finalized by a hairdresser that's local to you.

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Charna Goldsmith:

I'll ship them a wig that might be a little bit longer than what they're looking for and they can have the wig put on their head and cut on them in person.

Charna Goldsmith:

They have the option of changing or making any final touches. I think that really brings the customization process to a close and really gives them back a piece of themselves.

Laura Cohen:

I had caps and I had different hair coverings and nothing really felt like me. Nothing really felt feminine enough to give me back that feeling.

Laura Cohen:

And the first time I put the wig on my head, I just thought, "Wow. It's hard to express, but thank you."

Charna Goldsmith:

Being able to create virtually anything that a client wants or desires is probably the greatest experience in being a wig maker.

Charna Goldsmith:

We're able to meet these women's needs and design anything that they can imagine, whether it's a wig that they want to be made to look like their natural hair or something that's completely different.

Charna Goldsmith:

We've had clients that have requested us to make them purple wigs and we're able to do that for them. Making wigs for women that are going through chemo and being able to give them these custom beautiful pieces provides them with the dignity that they deserve and hopefully brings them a little bit of comfort in their journey along the way.

Melissa:

That was great. Okay. Finally, I want to welcome Emily Steinberg, who is a yoga instructor at the St. Louis JCC, which has been a Sharsheret community partner for many, many years.

Melissa:

Emily has been teaching yoga, mindfulness and breath work for 20 years. And as I mentioned at the beginning, not only are there these other things, but there is a holistic component to it.

Melissa:

So Emily's going to talk about that. Welcome.

Emily Elizabeth Steinberg:

Hi, hi. Welcome, you guys. Thank you so much. Lovely to be here. My name is Emily Elizabeth. I teach the Yoga for Cancer virtual class online and I've been doing that for quite a while.

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Emily Elizabeth Steinberg:

And when I think about our group, what I love the most is the community of all of us coming together every week and it feels very much like a support group.

Emily Elizabeth Steinberg:

So one of the first things we do is just connect with each other and share. There's a common thread that everyone has. For me personally, I've been teaching for 20 years, but how I landed, like why I'm here, is my mom had cancer for about 22 years, five different kinds, BRCA gene mutation.

Emily Elizabeth Steinberg:

And then I came to find out that I also had the same. And this was back in 2010 but I went through preventative mastectomy and reconstruction in 2010. I did the hysterectomy and oophorectomy in 2014.

Emily Elizabeth Steinberg:

So although I haven't gone through the cancer journey, I watched my mom go through it and it's close to my heart. Forgive me, I'm a little bit nervous, but it's so lovely to be here.

Emily Elizabeth Steinberg:

So cancer is close to me, especially watching my mom and being there for her for all of those years, five different times that she had it.

Emily Elizabeth Steinberg:

So our group, we support each other and there's a connection, so I love that. And I think people love that the most. When we think about just the physical benefits of yoga, flexibility and strength and balance.

Emily Elizabeth Steinberg:

Of course, there's so many benefits to just supporting the immune system, supporting the nervous system, supporting the lymphatic system with breath and movement. So physically there's lots of benefits, of course.

Emily Elizabeth Steinberg:

We want to be stimulating the lymphatic system and so much of that comes from breath and movement. And so the practice we're trained in, we're very cautious and careful.

Emily Elizabeth Steinberg:

There's postures that we're not going to do. There's breath work that we're not going to do. I'll do a little demonstration at the end here. So there's the physical benefits.

Emily Elizabeth Steinberg:

For me, the emotional benefits are just as important. Learning to drop into your body in a different way, learning to listen to the messages of the body, to begin to feel safe in the body again.

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Emily Elizabeth Steinberg:

So much of it for me, of course, I get excited about the physical benefits, but the emotional benefits I think are so important. I do a lot of that and I love that.

Emily Elizabeth Steinberg:

So spirituality comes into play just by connecting into yourself. So that's always there for me. But I would imagine having gone through a cancer journey there's a need to feel safe in the body again.

Emily Elizabeth Steinberg:

So the mindfulness, the breath work, the presence, and we're small but mighty, our group. But I think that we create this container where it's ritual and every week we come together and it is time for me, it's time for me, meaning the students that show up. This is my time to self care, to breathe, to be present, to listen to the messages of my body.

Emily Elizabeth Steinberg:

Yeah. So I think I'm going to do a little bit of a demonstration and I think some more information will come through as well.

Emily Elizabeth Steinberg:

One of the things that I want students to feel when they come is safe. Safe to share whatever they're going through that they want to share. And if people don't want to, they don't have to.

Emily Elizabeth Steinberg:

And safe moving through the postures and knowing that really one of the things that I focus so strongly on is in every moment you're making choices that feel wise to you and to be listening to that.

Emily Elizabeth Steinberg:

So if something doesn't feel right, you don't do it. And the freedom in that. But yoga, of course, has done it for so long. The mindfulness piece, the physical practice is so powerful.

Emily Elizabeth Steinberg:

And in Yoga for Cancer, we've got this common thread that everybody's going through together and we get to lean into each other.

Emily Elizabeth Steinberg:

And I hold the space and I do teach it from a perspective of a deep understanding and yet a respect that they're my teachers too, because I've not walked it in the same way.

Emily Elizabeth Steinberg:

Okay. I'm going to teach a little. What I invite you to do is if nothing more breathe with me and maybe just visualize yourself moving through the postures.

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Emily Elizabeth Steinberg:

There's a lot of it we're on our back, a lot of it is breath work visualization, and we want to get the body moving because we want to get the blood flowing, we want to stimulate the lymph, we want to build strength. Even the weight bearing for the bones. The benefits are many.

Emily Elizabeth Steinberg:

Okay. I'll do a little demonstration. We don't do things like downward dog. We don't do a lot of inversions. And it's so gentle. It's very gentle.

Emily Elizabeth Steinberg:

And Yoga for Cancer class, we use two blocks. I know it's dark in here. I apologize.

Melissa:

We see you. It's better down.

Emily Elizabeth Steinberg:

Okay. It's better with this down?

Melissa:

Yeah.

Emily Elizabeth Steinberg:

Okay. Thank you. All right. So we just come into stand, into mountain pose, we bring the hands to the heart and just find your breath. Take a nice big breath in with me and a full breath out.

Emily Elizabeth Steinberg:

On your inhale, we reach the arms up. And as you exhale, you're going to come into chair pose and you bring your hands to the blocks. So I keep my back nice and straight. My legs are strong.

Emily Elizabeth Steinberg:

I'm going to press into the block and step my right foot back and bring my right knee down. So we go nice and slow. Inhale reach the arms up. I'm going to do one on each side. Exhale bring the hands down.

Emily Elizabeth Steinberg:

So we're moving in rhythm with the breath. Inhale lift the right leg and exhale we step back to chair. And I go nice and slow. Push to stand. You can feel your heart elevate a little bit. And exhale.

Emily Elizabeth Steinberg:

More intentional really, I am always guiding my students to be intentional with what you're breathing in, what you're breathing out, what you're receiving, what you're letting go of. So that it's almost like prayer or intention, positive with every breath.

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Emily Elizabeth Steinberg:

Inhale arms up. Exhale to come down. The left leg steps back the left knee releases down as you exhale. Inhale arms reach up. Exhale. Inhale. Exhale.

Emily Elizabeth Steinberg:

So I breathe loud because I want, not that you have to breathe that loud, but I want people to be following in that way. And I'll have students that will come and they won't do the physical practice.

Emily Elizabeth Steinberg:

They'll be, "I'm tired today. I want to lay down but I want to hear your voice. I want the visualization. I want the positive intention and I want the connection," and I welcome it.

Emily Elizabeth Steinberg:

So really everybody shows up and does exactly what serves them in the moment. Yeah, I think that's it.

Melissa:

That's wonderful, that's wonderful. I can get a sense of how this type of activity really does compliment the other things we've been talking about.

Melissa:

I'll be honest that when we started this program, I thought it was great we were doing this complimentary offerings, but I didn't make the connection.

Melissa:

And now I understand the connection, right? It helps with self-care and the way we envision ourselves so thank you.

Emily Elizabeth Steinberg:

You're welcome.

Melissa:

Right. Somebody's already saying even that short bit was therapeutic.

Emily Elizabeth Steinberg:

Okay. Thank you. Yeah.

Melissa:

Absolutely. I want to get to your questions. So we received a good number of questions and we'll get to as many as possible. But I want to clarify something first.

Melissa:

Before we answer any questions, any questions you have as participants tonight that are about applying for or receiving any BFF 2.0 resources, should be addressed to clinicalstaff@Sharsheret.org, which is in the chat box right now.

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Melissa:

To receive any of these benefits you have to start the process with Sharsheret and not the opposite way. So you wouldn't call any of these places directly. You call Sharsheret. We make the connections for you.

Melissa:

Okay. Let's get to these questions. Or you can start online, yes, that goes in the chat box also.

Melissa:

It's interesting, Emily, that you mentioned that you don't do a lot of inversions because somebody did ask, is it possible to do downward dog? And if not, why is that the case?

Emily Elizabeth Steinberg:

I think we're mindful of anybody not getting dizzy. We don't want to do anything that's going to cause anxiety. If a student wants to do downward facing dog, I'm a believer that it's a listening in.

Emily Elizabeth Steinberg:

It's a deeper relationship with self and you know what's best. And if there is an intuition, "That that's not right for me, I'm not going to do it." And if there's an intuition of, "I want to do this."

Emily Elizabeth Steinberg:

So in a way I'm a believer of really listening to the body, but we try to keep things gentle. Somebody commented I'm not comfortable with some of those movements.

Emily Elizabeth Steinberg:

And that's the other thing I want to stress is that there is so much that we can do. There's so much that we can do and there are things that are important to not do.

Emily Elizabeth Steinberg:

Like for instance, in yoga pranayama breath work, in a typical class, I might teach, "We're going to take a deep breath in for count of five. We're going to hold it for five. We're going to exhale for 10."

Emily Elizabeth Steinberg:

We don't do breath retention. We're not taught to do breath retention because that might trigger. So there are things that we're specifically taught not to do. Yeah.

Melissa:

Yoga for Cancer is a little bit different than going to a regular yoga class, which is why if you're in an area that has that, you might seek that out or you might find some videos online at the Sharsheret website or elsewhere, because there really is a difference. Thank you.

Emily Elizabeth Steinberg:

Yeah, yeah.

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Melissa:

Okay. So I have a couple of questions for Mandy and for Teion. So one question is that someone says they had areola and nipple tattooing, but the color doesn't match the real remaining breast.

Melissa:

And is it possible that it can be fixed after it's done if you're not satisfied with the results?

Mandy Sauler:

Yes, absolutely can fix it for the most part I would say. Usually I would have them send us photos or we can consult them.

Mandy Sauler:

But in majority of the situations that happens, the colors usually faded at that point, which leads into another question that I did see on there that says that they've had it done several times and the pigment have faded.

Mandy Sauler:

This is a little different because we're using different inks. There's also multiple reasons why the ink could have faded over time or maybe the color's not matching.

Mandy Sauler:

There's a different line of inks now where you can really match any skin tone from anywhere around the world and match that areola.

Mandy Sauler:

So I have a set that I developed that's sold all over the world that you can match a unilateral. So if you only have one side matching is a very difficult task, but with this set, you should be able to match any unilateral with that set.

Mandy Sauler:

And also just redoing an areola that has maybe faded. Maybe I've had it done two times, or maybe I've had it done four times, I've had the tattooing and didn't hold.

Mandy Sauler:

It could be multiple reasons. It could have been the process that the person did. It could have been the ink that they used.

Mandy Sauler:

We did a study at the University of Penn Medicine, and we did the two different types of inks. So think of it as like you have an iron oxide ink where it's going to fade over time.

Mandy Sauler:

And you think you think of people with traditional tattoos and you're like, "Why is my nipple tattoo fading when these people are walking around with tattoos all their lives. What's going on? Why do I have to go back two, three, four times?"

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Mandy Sauler:

So these pigments are more heavily pigmented, so they're going to last longer. So what we use is we use these type of inks that are going to last longer over time. It just doesn't make sense for the client to have to keep coming back over and over and over again.

Mandy Sauler:

So usually what we do is it's one procedure, in some cases it's two, because you have to remember you're working in skin that's been compromised.

Mandy Sauler:

So you have scar tissue, you have all these things. So maybe two, but from there on it should be good. You should be good for a long time.

Mandy Sauler:

Unless you do topless beaches or something, I don't know, sun exposure, I'm just trying to be funny, sun exposure will fade the tattoo, so we do get sun through our bathing suits and things like that.

Mandy Sauler:

So you just want to protect it, but otherwise yes, we can absolutely correct work. We do a lot of correct work.

Melissa:

So another question we received was some people's plastic surgeons say, "Oh, you don't have to go to a special tattooist. We can do it as we're putting your implant in," or doing whatever.

Melissa:

So can you talk to us about the difference between having a plastic surgeon do it versus someone who works at your Institute or other similar places?

Melissa:

And then the next question we got is the differences between a medical grade tattoo versus just a regular tattoo? So my understanding, and please correct me if I'm wrong, is that medical grade tattoo doesn't necessarily mean you had it done in an operating room when you were having surgery. Those are two different things we're talking about.

Melissa:

So could you explain all that, clear that up?

Mandy Sauler:

Okay. Yeah. So the difference between a doctor doing your tattoo is a doctor is trained to be a doctor. A tattoo artist is trained to be a tattoo artist.

Mandy Sauler:

And let's be realistic, I'm good with my hands, but that doesn't mean I can go into the operating room and do a plastic surgery.

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Mandy Sauler:

But a doctor thinks, "Since I'm a doctor, I'm good with needles that I could possibly do a tattoo." So you have to be an artist. I think that's more too. You have to be trained in these type of procedures.

Mandy Sauler:

We train people over the world to do this, and it's an art. So it is, it's an artistic thing that you have to know and learn and really learn the whole process.

Mandy Sauler:

So I think that you may be able to find someone in the medical facility that's properly trained to do this type of procedure, but it just depends.

Mandy Sauler:

I would just do your research diligently for that part of it if you are going to have someone in the medical facility do that. Do ask them what type of inks they're using.

Mandy Sauler:

No, there's not necessarily a medical grade tattoo per se, I would say. It's not something that's done in a OR. When we do our tattoos, and all of our artists all over the United States do our tattoos, it's done in a professional setting.

Mandy Sauler:

It's done in a clean room. Everyone is blood borne pathogen certified. So you're getting up to the standards that we're going to provide.

Mandy Sauler:

Or if you're looking for an artist in the state that we found for you guys, that's what you're going to find. Someone that's qualified in all those and safety aspects of tattooing.

Mandy Sauler:

You're not going in someone's house and using dirty needles and things like that. So that's what we wanted to provide for everyone.

Melissa:

Okay. Thank you so much. Okay. A couple of questions about scalp cooling. So one of them is, are there any side effects to scaling both immediate or long term?

Bethany Hornthal:

That we-

Melissa:

Bethany, I can't hear you. Perhaps other people can. No. Okay. So we're going to go on to another question with someone else while we figure out what's going on with your computer.

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Melissa:

Okay. One of the other questions we got, somebody had an interesting question for Teion, which was the SMP, I hope I got that right?

Melissa:

What happens when hair begins growing in again and either comes in gray but you've tattooed it, the color of the original hair or somebody chooses to dye?

Teion Milbourne:

So the goal for that is SMP just creates a overshadow of the scalp. All right. Remember it's just tiny hair follicle pigments I [inaudible 00:46:04] with a tiny microneedle.

Teion Milbourne:

So if your hair is growing in gray, it doesn't have anything to do with your overshadow underneath the scalp. But you would have to come in probably every three years to get a touch up.

Melissa:

That's far less frequently than getting hair dyed, so I still count that as a win. Thank you.

Mandy Sauler:

Better than using those powders and those talc powders that people put on their scalps for hair thinning or spots and things like that.

Teion Milbourne:

Yeah.

Mandy Sauler:

Yeah.

Melissa:

Okay. Thank you for that. Somebody asked, do you see women who have chosen to go flat as opposed to opting for reconstruction, choose to also have nipple and areola tattooing?

Mandy Sauler:

Yes. I haven't saw a ton of women that done that, but I know women have done traditional tattoos that way. I have done areola tattooing on someone that didn't have reconstruction. So that's definitely an option for someone that hasn't had reconstruction.

Melissa:

Okay. All thank you for that.

Bethany Hornthal:

I think I might be back.

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Melissa:

You are back. Okay. So we were talking about side effects, both immediate and any long term.

Bethany Hornthal:

Okay. So the biggest side effect of scalp cooling is just how cold it is and of the 102 participants in the trial, two decided that it wasn't comfortable enough that they would continue.

Bethany Hornthal:

So it's very rare that somebody will stop for that. And nowadays what's done usually is that you might have a Tylenol before you get started. You might even have an Ativan before you get started.

Bethany Hornthal:

It's like a brain freeze for the first five or so minutes. So you can liken it to that. If you're doing the automated scalp pulling with a machine, which is in about six to 700 facilities, they gradually cool it down.

Bethany Hornthal:

After about five, six, seven minutes, your scalp is numb. So you no longer feel cold from that. You may feel cold, but you won't feel that feeling long term. It's not an invasive technique.

Bethany Hornthal:

It's just applying ice, notice, but it's applying cold to an area of the body. So as long as it's done professionally, and the reason the FDA has cleared the automated devices and not the manual ones, is just because there is a slight chance that if you take a manual cap off of dry ice and you don't know what you're doing, you could have some frozen burn situation. It's very rare, but it can happen.

Bethany Hornthal:

But other than that, the side effects might be a headache from the cold initially. But usually a Tylenol is what's administered and on they go.

Melissa:

And another question is automated versus manual. You've explained why one is FDA approved and the other isn't, but is there more success with one versus the other?

Bethany Hornthal:

So we have this thing called practice makes perfect. With scalp cooling it's like anything else, whoever is operating the scalp cooling is going to have some impact on how effective it is.

Bethany Hornthal:

Between automated and manual, they can be both as effective. And in fact, with manual, you get to take it home if you want and you can continue longer. And there is an argument that with some chemotherapy regimens, the most toxic, maybe that is a better way to go.

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Bethany Hornthal:

But really when a nurse oncologist has worked several times with scalp cooling in that infusion center, they get pretty darn good. And they're the ones who are administering scalp cooling in a hospital setting in an infusion center for automated.

Bethany Hornthal:

For manual, you are always going to be bringing that either with, if you can afford a professional capper, you can bring someone in with you or partners, friends, family maybe helping.

Bethany Hornthal:

And some women I know have had this gaggle of women who come with them to each scalp cooling session or whatever, or each one, and they switch off which is wonderful for the person, but they have to relearn something or learn something new each time. So those are the issues of effectiveness.

Melissa:

And I actually saw in the chat box just now that the scalp cooling doesn't necessarily work with every treatment protocol. So it's more effective with certain treatment protocols, certain chemotherapy drugs than it is with others?

Bethany Hornthal:

Yeah. So scalp cooling is going to depend on a few things. It's going to depend on the level of toxicity of the treatment.

Bethany Hornthal:

The most toxic treatment women are familiar with the term, the Red Devil or Adriamycin and Cytoxan. That is one of the most toxic therapies that are used effectively.

Bethany Hornthal:

And it's interesting. We have situations where patients have been unable to maintain the majority of their hair or have lost most of their hair with AC. But I know a 32 year old who swears she didn't lose a piece of hair, so I know both sides.

Bethany Hornthal:

But the more toxic that regimen is probably the more hair thinning you're going to see. Also, it depends on the thickness of your hair.

Bethany Hornthal:

Interestingly enough, in African American hair, because it's as thick, it's a little harder to conduct the cold right down to the scalp.

Bethany Hornthal:

Now there's work being done right now on lotions and things that will help that.

Melissa:

Fascinating.

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Bethany Hornthal:

It's different things that will indicate how successful you'll be.

Melissa:

Okay. I wish we had time for more questions, but I do have to bring this to a close. So just a few more minutes. I want to, first of all, again, thank all of you for sharing your expertise and your passions with us today, as well as your experience, Laura-Lee.

Melissa:

I hope you all learned as much as I did. I want to thank our generous sponsors Daiichi-Sankyo and Merck. And before we close today, I just want to take the opportunity to share one additional Sharsheret resource with you.

Melissa:

Before we had BFF 2.0, we had our original BFF or Best Face Forward kit. These free kits were created to help women address the cosmetic side effects of treatment.

Melissa:

The kits all include paraben and phthalate free makeups and lotions. All of them include brow guides and instructions on how to use everything. The kit can be used on its own or in conjunction with 2.0 subsidies.

Melissa:

So right now in your chat box is a link to an evaluation survey on today's program. In addition to evaluating tonight's program, it will give you the opportunity to order your free BFF kit or to apply or ask questions about the BFF 2.0 subsidies. It's linked in the chat box right now.

Melissa:

And during the next few days, early next week, you'll receive a follow up email with a link to tonight's recording, a transcript, and access again to some of the resources we've discussed. So please be on the lookout for that email.

Melissa:

And please remember that Sharsheret is here for you and your loved ones during this time. We provide emotional support, mental health, counseling, and programs, such as the ones we've talked about tonight, to help you navigate through your cancer experience.

Melissa:

All are completely free, private, one on one. Our number is in the chat box right now, 866-474-2774. And of course you can email us at clinicalstaffatsharsheret.org. That was also in the chat box.

Melissa:

Remember, we'd love to stay connected with you through social media where we post about events like these, program updates. We actually just posted today or yesterday, a new study about cold capping. So lots of good information there.

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Melissa:

Thank you for joining us and have a wonderful evening. Good night.

Bethany Hornthal:

Thank you.

About Sharsheret

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

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

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

Sharsheret offers the following national programs:

The Link Program

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

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

Education and Outreach Programs

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

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