Jenna Fields:

Welcome everybody. We're going to get started. Thank you so much for being here. I'm going to ask Deborah to take down this slide and we're going to start today's webinar. Thank you so much for being here. I'm Jenna Fields. I'm the Chief Regional Officer of Sharsheret, and this evening you're joining us for Ovarian Cancer Awareness Month's Program, Navigating Ovarian Cancer, Enhancing Quality of Life. This webinar is the kickoff to Sharsheret Summit, which is our big marquee event for Sharsheret that brings together thousands of people, virtually and in person. And it's going to officially begin in October, but you can join us for all of our national virtual symposiums on the latest hot topics in ovarian and breast cancer. And you can also, during this time period, attend or host an in-person education and awareness raising program with community partners around the country, as well as learn the latest guidelines and access our most up-to-date information and our digital resource packet.

So please visit our Sharsheret Summit website to learn more about the summit, to register for additional webinars and to gain access to information throughout the Summit time period. My colleague Deborah is putting information about Sharsheret Summit in the chat right now. I just want to draw your attention to our upcoming webinar next Monday, September 9th at 8 PM Eastern. It's our Sharsheret Ambassador training. And this is for those of you who want to share your story or represent the ovarian cancer community at community events across the country.

So please register for that if you want to learn more about speaking and representing Sharsheret at community events. We're grateful for tonight's webinar sponsors GSK and Immunogen, and we want to thank our Sharsheret Summit sponsors as well, AstraZeneca, Daiichi Sankyo, Merck, Pfizer City of Hope, Orange County, Eisai, Northwell Health Cancer Institute, and RMA New York, Long Island.

Now, before we begin just a few housekeeping items, today's webinar is being recorded and it'll be posted on Sharsheret's website along with a transcript. Your faces and names will not be in the recording, and if you really want to remain private this evening, you can turn off your video or rename yourself or you can call into the webinar and those instructions are being put into the chat now. We also now have closed captioning available. So instructions on how to access them are also going to be placed in the chat.

Please keep yourself on mute throughout the presentation, and if you have questions at any time, please put them in the chat box either publicly or you can submit a question to me privately. We will have a Q&A at the end of the webinar. Please for all your questions, make sure they're as general as possible as we cannot offer specific medical advice. And we'll do our best to answer as many questions as we can.

Following this webinar at 9 PM Eastern, 6 PM Pacific, the doctors will stay on for a more intimate Q&A exclusively for our Embrace community. That's those who are facing advanced or recurrent ovarian cancer. I want to remind you that Sharsheret is a national nonprofit organization and does not provide any medical advice or perform any medical procedures. And the information provided by Sharsheret is not a substitute for medical advice or treatment for specific medical conditions. You should not use this information to diagnose or treat a health problem. And if you have any questions that are specific to your medical care, the doctors will not be able to advise regarding specifics and would advise that you speak to your medical provider. Please always seek the advice of your physician or qualified healthcare provider with any questions you may have. Now, before our experts begin, we'd like to welcome Joan Frankel who will share her personal story of her ovarian cancer journey. Welcome Joan.

Joan Frankel:

Thank you Jenna, and good evening everyone. So I've known about Sharsheret for a while, even before I was diagnosed with ovarian cancer. My synagogue sponsored Pink and Teal Shabbat programs in previous years, and some of the speakers were Sharsheret champions, and they shared amazing stories and slideshows. And they were also active peer supporters. Little did I know that I would one day shortly thereafter be seeking support from Sharsheret. So going back about five and a half years in May of 2019, my family was planning an amazing trip to Greece. It was for my mother-in-law's special birthday. And

my kids went along, my sisters-in-law, all the spouses, and we really were planning a wonderful trip. It was terrific. We are all ravenous eaters. We loved the Greek food. However, my stomach was starting to get very distended. And I kept thinking to myself, "Oh, we're just eating too much."

I mean, we sit down at a meal and we talk about our next meal. I was feeling very full, very quickly, and I stopped eating three meals a day and my stomach never went down. Now, interestingly, I thought there were maybe two reasons for this. One possibility was that I had had for years a hernia, and doctors had told me not to do anything about it unless it was really giving me problems. In fact, I had recently had it looked at and there was no reason to do anything about this hernia.

The other reason was, well, I was 56 years old, gee, I must be going through perimenopause into menopause. And many of the symptoms like bloating are symptoms of menopause. But as soon as we got home from our trip, I immediately went to the walk-in clinic for my medical health and saw the doctor on call who set up for me to have a CT scan the next day.

And I was like, "Oh, I guess you need a CT scan if you're going to have a hernia operation." And my mom was calling me to say like, "Oh, so when's your hernia operation?" And one day later I walked into the doctor's office after already going into the portal. So I walked in knowing the word carcinoma was on my portal, and that was kind of scary. I was diagnosed with high grade serous carcinoma originating in the fallopian tube. It ended up being stage 3C, which was even scarier. And I was within a week on the operating table having the bulking surgery and the surgery went well. I am very grateful to every healthcare professional that is ever taken care of me and had gotten me so quickly to have surgery and to start my recovery and recovery included a lot of rest and a revolving door of friends and family checking in on me, bringing food for me.

It was the middle of summer, so my sister came from Maine and helped plant my garden, and I wanted to make things as normal as possible for my two young adult sons, and that was absolutely impossible. I also had genetic testing, which is another reason I came to Sharsheret. It turns out that I tested positive for the BRCA1 mutation. Now, the BRCA1 mutation, unknown to me if your father carries the BRCA1 mutation or your mother carries the BRCA1 mutation, it's the same odds that you're going to carry the BRCA1 mutation 50% if one parent carries it. And I was under the false impression that it was more likely to carry a BRCA mutation if it came from your mother's side. So I'm just putting it out there just in case people don't know. That's just not true. And quite often I meet people along the way who say, "Oh, my mother-in-law died of ovarian cancer."

And I'll say, "Well, has your husband been tested? You have daughters, you have sons. You ought to talk to them about getting tested." And I try to spread that word wherever it comes up in conversation. But my dad had died of Hodgkin's lymphoma when he was 38 years old and I was 10. So there wasn't really a good trail for me to have everyone in the family tested. Subsequent to my testing, my mother tested negative, so I knew it came from my father's side of the family, and his cancer didn't have anything to do with a BRCA mutation. But when he died in 1973, the mutation hadn't been discovered yet. So in preparation for chemotherapy, as I recovered from surgery, I got my hair cut very short, which would lessen the drama of losing long clumps of hair after chemo started.

And my chemotherapy included six rounds of the standard chemotherapy, Taxol and carboplatin, and three weeks in between treatments. So week one was horrible, week two was a little bit better, and I'm sorry I said that wrong. Week one was okay. Week two was horrible, and week three was much better. And during treatment, I tried to enhance the quality of my life, the theme of tonight's program with the things that I always liked to do, which was be with my friends, being with my family. But intense yoga became gentle yoga, and my running career became my walking career, lots of walking with friends. And that turned back into running shortly after my last chemo.

In fact, one of the big milestones, and one of my great memories was that my running girls insisted on running a very slow Turkey trot with me the Thanksgiving after I finished my chemotherapy treatment at my new very, very slow pace. But I wanted to also mention that I envelop myself of integrative medicine

because I wanted to talk to professionals about how to have good nutrition during treatment. And also I did acupuncture for side effects like neuropathy and hot flashes. And another thing that I was fortunate that I was treated at a hospital that had clinicians that were dedicated to female sexual medicine and women's health. That's kind of like the thing nobody wants to tell you about, but it's a very, very important part of recovery from my kind of cancer from ovarian cancer.

So until then, I hadn't availed myself of Sharsheret's programming, but I told you I knew what Sharsheret was. I started attending Zoom programs in 2020 during COVID. And in March of 2021, someone I knew who had written a book, spoke on a Sharsheret webinar. So I was on that, and eventually I consulted with Peggy, the genetic counselor about genetics and how and when to share information with loved ones and different testing options. And actually fast forward to 2023, Peggy and I participated on a Zoom panel at my local synagogue.

I continue to receive check-ins and good counsel from Bonnie who's on the webinar tonight and even five years post diagnosis, it feels very safe to keep our connection. Now, since I'm not a medical professional, volunteering has been a huge part of my post-treatment life. I have volunteered at the hospital where I received treatment, and I'm a member of its patient and family counsel for quality. But some of my best volunteer experiences have been through Sharsheret as a peer-to-peer volunteer. I hope I have helped people navigate their challenges before, during and after treatment. I have spoken to and commiserated with wonderful women, and even as we put our cancers behind us, hopefully we have continued to stay connected. And so thank you for allowing me to share part of my story with you tonight, and I look forward to the rest of the program.

Jenna Fields:

Thank you so much Joan for sharing your story, and you are now a Sharsheret ambassador in our webinars as well. And I love hearing that you connected through some of our webinars during the pandemic. Thank you so much for inspiring all of us. It's now my pleasure to introduce our speakers who are not only experts in the field, but also brothers who work alongside each other serving the gynecologic cancer community at City of Hope of Orange County. We are going to start with Dr. Josh Cohen, who is the medical director of the Gynecologic Cancer Program at City of Hope, orange County, and I'm excited to also share that we're honoring him in Los Angeles on Sunday September at our annual West Coast Dash 5K, 10K family fundraise where you can participate in person or as a virtual racer. So for all of our Southern California folks on this call, I hope you'll join us at the race. And my colleague Deborah is going to put Josh's extended bio in the chat as well as information about the race. So it is now my pleasure to introduce Dr. Josh Cohen.

Dr. Josh Cohen:

Thank you very much Jenna for the kind introduction. Also a huge thank you to Joan for sharing your story. You're a true inspiration and you're why we go to work every day. And so I just love hearing how people are doing and please thank you for all that you do to volunteer and share your story and reach out to others because that's so important for women to hear what life is like and how life does go on for all patients in various ways. So truly thank you. I'm going to go ahead and share my slides now. So I'm going to talk for about 20 minutes here. And then Dr. Seth Cohen, my twin brother will start. I'm 20 minutes older. He's a little taller, and I tell the story he got more food. He was in there longer, so that's why he's taller, but that's okay.

Okay, so we're going to talk about ovarian cancer and enhancing quality of life. I do want to just say September is Gynecologic Cancer Awareness Month. And certainly ovarian cancer is a huge part of that in addition to other cancers, uterine cancer, cervical cancer, vulvar cancer, vaginal cancer. And so this is our opportunity to really get the word out about these cancers, to ask for research funding from the government, from those who have resources. And sadly, 30,000 women will unfortunately die this year from gynecologic cancer, but we're helping in curing so many more. And so I just want to say just if

you're out there and you've been impacted by this, whether it's your family or you, get the word out, talk to your local synagogues, talk to your local religious agencies, talk to your local government and try to generate support for research in these areas.

Ovarian cancer, approximately 20,000 women in the US will be diagnosed with ovarian cancer this year. And this represents 1% of all new cancer cases, which is still fairly rare. But the challenge that we face with ovarian cancer is that unfortunately for most patients when it presents, it's a disease that's already spread within the abdominal cavity. And that's why we really want to do everything possible to find it earlier. And we're making some strides there in diagnosing cancer earlier, but we're also making strides in treating this cancer, which we're going to talk about.

And although it's a rare cancer, you can see on the list of cancers that impact women, it's still the fifth leading cause of cancer death here in the US. And so we want to acknowledge that and do better and we are doing better. We talked a little bit about BRCA1 with Joan's story, which is so very important. And my name's Josh Cohen. I'm an Ashkenazi Jew, but we know that genetics plays an important role in ovarian cancer, about 20% of ovarian cancer. And when I say ovarian cancer, that also includes fallopian tube cancer and primary peritoneal cancer. 20% of these cancers are related to the genes we inherit from our mom and our dad.

And so if someone has a issue of Ashkenazi Jews in their background, you have a one in 40 chance of having a BRCA mutation. There's currently 60 people logged on to this event. If none of us knew about our history and you tested all of us, one of us is going to have a mutation given there are probably at least 40 Ashkenazi Jews logged in, one in 500 in the general population, that means all comers, so all people.

So if you go to the mall and look around, every 500 people you see, one person will have a BRCA mutation, and we know that BRCA mutations are passed down equally from moms and dads. And that's something that I often hear from patients, as you heard from Joan that, "Well, my mom's side of the family, there's no history of cancer. I don't know why this developed." And then when we go back a little bit further, we find out that dad's brother had prostate cancer and dad's mom had breast cancer.

And so we have to keep that in mind to know our family history because the best way to treat cancer is to prevent it. And Joan has saved the lives of many people in her family by getting genetic testing and probably communicating that with her family so that they can get tested and we can take measures to prevent cancer developing and the other family members who may have the BRCA mutation.

And so there is also increasing data about the risk of BRCA in Sephardic Jewish population. But regardless of your background, know your family history, and if you have a significant family history of cancer, talk to your medical provider, get the right genetic testing, talk to Sharsheret. They offer free genetic testing counseling through the organization. Seek out a genetic counselor. Genetic predisposition to gynecologic cancer is not just BRCA1 or 2. There are many other mutations, and it's not uncommon that I'll hear from someone. My family got me a free genetic testing kit for Hanukkah for Christmas a couple years ago. I sent it in and it was negative. Why is this happening? And the truth is, it wasn't a good test or maybe it was a small test. And so people are now doing direct testing from families as gifts. People are doing testing online through direct marketing from companies, but just know that may not be the best testing.

Also know that the insurance companies will only really cover one test. Once you've had your genetic testing, they'll often come back and say, "Hey, Dr. Josh Cohen, we've already paid for Ms. So-and-so's genetic testing. Guess what? We're not paying again." And so it's really important to try to get that best genetic test the first time. And that's why if you can seek out a genetic counselor through Sharsheret or if you're at a place that you can have a genetic counselor or referral through your primary care doctor, please do that. But try to get that first genetic test to be the right genetic test for you based on your family history.

There's also, in addition to the blood and saliva tests, there's a lot of information that comes with that because if someone does test positive, you really want to have a medical provider, whether it's a genetic

counselor or a physician, go over the results with you and discuss what are the risk-reducing measures we can take to prevent cancer? Or what are the screening tests that you need? For example, if you have a BRCA1 or 2 mutation, you're going to need mammograms or breast imaging more frequently. You would need to discuss the role of potentially a risk-reducing surgery to remove breast tissue, the role of removing the ovaries and tubes, maybe not for everyone, but something that should be part of the conversation.

Genetics can be a little bit complex, but I really just want to break it down into two parts. One is the genes that you inherit from your mom and your dad. The other are the genes that are in the tumor cells if someone has a tumor. And so most cancer, 80% of ovarian cancer is related to spontaneous mutations in the DNA of the tumor. So every second of our lives, our cells are dividing and the blueprints in our cells are very specific. It just takes one error in the blueprint for the cell to go awry and turn into cancer. And that's the spontaneous mutations called somatic mutations.

Germline mutations are the mutations we inherit from our mom and our dad, and it's in every cell in our body. And if you have a BRCA1 mutation in every cell in your body, it just takes one more error in that blueprint to cause cancer. And that's why patients are higher risk for cancer who have a genetic predisposition, but just know that mom and dad, either one can pass a genetic mutation on to their offspring. We've talked a little bit about that. This know your family history, ask to see genetic counsel or physician with a focus in genetics. The other challenge with genetic testing results is that there, it's not always clear cut.

And for those patients who have had genetic testing, sometimes we get a result called a variant of undetermined significance or VUS. A VUS is basically an abnormal finding in that it's not common, but it's not necessarily a harmful mutation. It could just be a rare version of normal, and you really want to have a medical professional interpret that and say, Ms. So-and-so or Mr. So-and-so, your BRCA result is not a harmful mutation. It's just a rare form of normal, so we don't think you need to do additional screening or testing.

And also these tests have implications for your families. Clearly if you test positive, it could be life-changing for your family, and it's important to keep that in mind, which is why you would want to seek out a medical professional if possible when you're undergoing genetic testing. This is a busy slide, but I presented because not all ovarian cancer is the same. In fact, we now know ovarian cancer is not the right term. It's a misnomer. It's really fallopian tube cancer for most. We believe that most cancers arise from the end of the fallopian tube. The fallopian tube is the highway. It's like the five freeway here in California when you travel, it's when you have an egg from an ovary, it travels down that highway into the uterus. So most of these cancers come from that highway. And we now know that there are other forms of cancer that we call ovarian cancer that may not originate along that highway.

The highway cancer is called serous cancer or high-grade serous cancer, which Joan had mentioned. But there are other forms of ovarian cancer called clear cell carcinoma, endometrioid carcinoma, mucinous carcinoma. And I'm sure there are people that are listening now to this presentation that have forms of these cancers that are characterized as such. The reason I bring it up is that there are different treatment options potentially for these patients in the recurrent setting, and it's an important for you to take ownership of this and know what type of cancer that you've been diagnosed with or maybe your family member's been diagnosed with because it has implications for treatment options for you moving forward.

We have different types of treatments for ovarian cancer, fallopian tube cancer, and peritoneal cancer, and that list is growing by the day. We've had five FDA approvals for gynecologic cancer in the last year, and we had a period of about five to six years where we had none, but five new treatments that the FDA has said insurance companies have to pay for is amazing. And every day we're getting new treatments and it's a really exciting time to be a cancer doctor because I have so many more things I can offer patients to help treat their cancer and hopefully improve their quality of life with better treatments that are less toxic.

Some of the treatments include chemotherapy, which is the tried and true standard of care. We have targeted agents, hormonal therapy, immunotherapy. We use surgery, radiation, integrative medicine. This is all part of your toolkit for your cancer doctor to use. I had the bark of the tree here because chemotherapy Taxol actually comes from a tree. So when I have patients who tell me, "Dr. Cohen, mm-mm, I'm only going natural treatments. No chemo for me." I say the most natural thing we can give you is Taxol because that com.

Es directly from a tree. But that being said, it's an open discussion with everybody at what we're doing. Ovarian treatment has become much more complex. It's no longer just one operation. It's no longer just one chemotherapy couplet. There are many different combinations, and you want to find a gynecologic oncologist like myself to help work with you in that setting when there's concern for cancer. It usually starts with a combination of surgery and chemotherapy. You usually want to get to a comprehensive cancer center. These are larger cancer centers that the federal government has designated as a National Comprehensive Cancer Center Network provider, NCCN, and they offer a number of services that are really part of the standard of care for gynecologic cancer treatment.

Surgery is a mainstay. It involves a tumor debulking, which again you heard Joan describe as part of her initial management with the staging surgery and then additional treatment with chemotherapy. Clinical trials are amazing and a wonderful option for our patients, and I'm going to mention those as well, but ask about life after your treatment. So one of the things that we're talking about today is how to improve quality of life. Life doesn't stop just with the last chemotherapy. Life has to continue on, and we need to anticipate some of the problems that we're going to cause with chemotherapy to make sure that your quality of life is better after.

There is a role for certain drugs called maintenance therapy, which is our drugs that are meant to keep the cancer away for longer or to prevent the cancer from coming back. An example of that is a PARP inhibitor, P-A-R-P inhibitor, which is now an oral pill available for certain patients who have a BRCA mutation in the somatic or the tumor DNA or in the germline DNA, which is again the DNA from your mom and your dad. And you should have an open discussion with your provider, what life will look like after your initial chemotherapy.

"Hey, doc, am I done? Do I have another year of treatment?" It's not uncommon that I'll see patients for a second opinion and they'll say, "Dr. Cohen. I had no idea that Dr. So-and-so wanted me to be on a drug called Bevacizumab that's in for another year. No one ever mentioned that." But it has implications because you need an infusion every three weeks. So what if you plan that once-in-a-lifetime trip in six months, and now you're being told you need treatment every three weeks. So these are things to think about.

Other options include heated intraperitoneal chemotherapy directly in the abdominal cavity. We're very fortunate at City of Hope where I am as a comprehensive cancer center, we offer this, it's called HIPEC for our patients undergoing initial treatment for ovarian cancer. A new revolution in ovarian cancer treatment is something called antibody drug conjugates. I call these smart bombs or Trojan horses. These are targeted therapies that go to the cells that only have the receptor for the linker on this target, and it's different than standard chemotherapy. Chemotherapy is like an atomic bomb. It just goes in and attacks everything.

These will find those cancer cells and really hone in on their receptors and then attack them. And so ADCs represented a very exciting new treatment modality for ovarian cancer patients. PARP inhibitors are personalized medicine. As a perfect example, I mentioned if you have a BRCA1 or 2 mutation in the tumor DNA or your DNA, you should get this PARP inhibitor. We also know that patients who have a certain molecular profile, even if they're not a BRCA1 or 2 mutation carrier, will benefit from a PARP inhibitor if they have a molecular called HRD, homologous recombination deficiency positive. And I think some of you are probably thinking, "Oh yeah, my doc did mention that they tested me for this." Or, "Hey, you know what? I haven't been tested for this yet."

So these are things to think about. Immunotherapy is a great hope for cancer treatment. It's part of ovarian cancer treatment. It's not a standard of care yet, but we're getting better at ways to figure out how to use the immune system to attack cancer. Car T-cell is the next real form of immunotherapy. We trained your T-cells to attack cancer. City of Hope is leading the charge in this as our other cancer centers across the country.

Using your own T-cells, we train them, we say go attack, and we send them back into your bloodstream and attack the cancer. We're not there yet, but gosh, we're close. We're close guys. It's going to happen. Pressurized intraperitoneal chemotherapy, which is an aerosolized form of chemotherapy delivered in the abdominal cavity, really a new way to deliver chemotherapy, and then clinical trials.

So what if there is a concern for recurrent ovarian cancer? We're trying to optimize your quality of life. We want you to live a long, happy, healthy life. We want you to get the best treatment possible. These are the things that I would think about in this setting. So meet with your medical team. Ask your team, "How do you know this is recurrence?" Oftentimes when I see patients again and they've said they've been diagnosed with recurrent cancer, I said, "Well, how do they know?" They actually haven't been told how they know they have recurrent cancer.

And so was it blood test? Was it imaging? Did they do a biopsy? Do you need a biopsy? And you should ask again who's involved in your care. Is it a medical oncologist who are great people, but maybe they see one GYN cancer a month? Are you involved with a gynecologic cancer doctor and is there a team working with you? Has your case been presented at a multidisciplinary tumor board where you have 15 to 20 gynecologic specialists, whether they're radiation oncologists, medical oncologists, gynecologic oncologists, all talking about you at the same time? Have you been able to get to an NCCN designated cancer center either via telemedicine or in-person and just know there's always more than one treatment? So if you meet a doc and they say, "This is your only option." I would ask that doc to rethink their approach or maybe get a second opinion because there's not just one answer to anything.

Things, again, to ask about where's the tumor located? What histology, subtype, serous cancer, clear cell carcinoma? Have you had the appropriate genetic testing? Is there a role for doing surgery in the recurrent setting if the cancers come back? Now, some of the newer agents, the newer antibody drug conjugates, there's something called folate receptor alpha. This is an antibody drug conjugate that attacks this receptor. HER2 is an expression receptor that's found in breast cancer, but also now to use to treat ovarian cancer.

Is the tumor sensitive to hormones? And what clinical trials are available for these targets? These are all ways we can potentially avoid chemotherapy and potentially maximize your quality of life. These are ways to lengthen your quality of life if we're giving you drugs that keep the cancer at a low volume but don't have as much side effects as standard chemotherapy. And then just other considerations are listed on the screen for you as far as the number of prior lines of treatment, your ability to do things that you want to do as far as your activities of daily living.

Have you had a prior drug such as Bevacizumab, also known Avastin? Have you previously been on a PARP inhibitor before? What are your other medical issues? Because if you have autoimmune disease, immunotherapy may not be a good option for you. Are you available? Are you able to have a clinical trial? If you've had many prior treatments up to four or five treatment lines, usually you can get onto clinical trial. But if you've already had maybe six to seven prior lines of chemotherapy, it can be really hard to find a clinical trial for you because many of these trials exclude patients who have been on multiple prior lines of treatment. And what are the ongoing side effects of the drugs we're recommending? Is it going to cause neuropathy? Is it going to cause vision changes? Is it going to make you feel really nauseated? These are things we have to talk about before we start the treatments because we need to ensure we're not wiping out your quality of life.

This is an example of the smart bomb I mentioned, or Trojan horse called antibody drug conjugates, Foley receptor one, HER2 and TROP2 are common targets. And we're going to finish up here just in the

last few minutes just with some kind of tenets of kind of what to think about. It's okay to ask for help, and it's really important to keep in contact with your family and friends.

When we think about quality of life, many of my patients when I initially talking, they're like, "I don't want to tell so-and-so I don't want to talk about this with my family. I don't want to stress them out. I don't want to stress them out. I don't want to make their life worse." But the answer is, they want to be there for you. They want to help you. And if you just bottle that up, if you try to take this all on in your own, your quality of life's going to suffer. And guess what? Their quality of life is going to suffer too. So be present. Now is the time to reach out to your family, reach out to your friends, ask for help. They want to help you. We want to help you. So lean on them. Lean on us. That's why we're here.

And again, when possible, seek an opinion with specialists. I know there are insurance barriers, but I can't tell you how important it's to try to get to a comprehensive cancer center because the quality of care is just going to be different. You're just going to feel different in that setting because there are more options for you. There are clinical trials, there are different functions than just giving a drug. And this speaks back to what Joan mentioned. She mentioned the sexual health support she received, some of the psychosocial health support she received.

Cancer centers offer more than just the cancer drugs. They offer symptom management. We offer nutritionists. We will offer mental health specialists. We offer integrative medicine. We have acupuncturists in our cancer center. We have meditation experts in our cancer center. So we have psychologists and psychiatrists. We've got people like Dr. Seth Cohen, who are going to talk to you about what they offer. So really, there's a lot more than just the docs who want to prescribe the cancer drugs or do the surgeries. And I'm one of those docs, so I can say that.

So messages of hope. One of the things that I often get from patients is what can I do? I feel like I've lost control of my life. What can I do? And there are many things you can do. And one of the most important is stay physically active. Keep those joints moving. Keep walking. Stay strong as much as you can, even if it's just getting up and walking around the kitchen table with a water bottle in each hand. Try to maintain muscle mass. Try to maintain your strength. If your strength is gone, we have very limited treatment options for you. Try to live a healthy lifestyle.

I get a lot of questions every week about CBD oil, about fasting, about alkaline water. I will tell you the answer is everything in moderation. A Mediterranean diet, living a healthy lifestyle but it doesn't mean you need to exclude sugar completely from your diet. If you want to, by all means, go for it. But gosh, if you're at your grandson's bar mitzvah or if you're at a bris or if you're at a baptism and you want to have that cupcake, it's okay to have the cupcake. It's not going to impact your cancer care. That being said, live a healthy lifestyle.

Everything in moderation, fruits, vegetables, whole grain, processed meats. These are things I would avoid, sugary drinks, highly processed food. I would tell this to anybody, whether you have cancer or not, as much as you can, try not to live CA125 to CA125 or CT scan to CT scan. I know that's easier said than done, but how are we helping you? If all we're doing is helping you live to the next scan? You're not doing the things you want to do. You're not living your life. Every day bad things happen to good people. And I don't know why that's the case, but I know you got to live your life. I know you got to say the things you want to say to your loved ones. You got to make the most of the time you have and whether you have cancer or not.

And I think one of the most important things we can do for our quality of life is make the most of it. And whether this is with cognitive behavioral therapy, talking with a psychologist, do that. Seek mental healthcare. We don't talk about it enough, but you can't just live scan to scan. It's not a way to live life. And avoid alcohol if you can. A little bit of Manischewitz is okay for Passover.

So just in summary here, a path forward, meet with your medical team. Advocate for yourself. It's okay to ask questions. I love questions. Consider a second opinion at an NCCN Cancer Center. There's always more than one treatment option. Reach out to your friends and organization such as Sharsheret. Lean on

people. Now's the time to do that. And cure is the goal, but it's not always possible. We can't cure everybody, but we can do a lot. And even if cure is not the goal, we can make things chronic. We can decrease burden here in Southern California. Everybody knows Magic Johnson, when he was diagnosed with HIV in the early '90s, we had nothing to offer him. We thought he was going to die. He's living a long, happy, healthy life because we made HIV chronic with antiretrovirals.

Now we're not there yet with cancer, but man, we're getting close. And with that, this is my email, other information. I'm going to turn this over to Dr. Seth Cohen, my younger, taller brother who can give you some really good guidance here on how to make the most of your quality of life. Thanks so much.

Jenna Fields:

Thank you so much, Josh. And I'm just going to set us up as Seth is getting set up. That was so informative. Really, so much to learn from your presentation. And now it's my pleasure to introduce your brother, Dr. Seth Cohen, who is the program director Reconstructive Urology and Survivorship Fellowship director at the City of Hope of Orange County. He's a urologist specializing in complex reconstruction of the pelvic floor, including fistula and pelvic organ prolapse repair. And we're going to put his full bio, the link to it in the chat. And please welcome Seth.

Dr. Seth Cohen:

Well, it's a real honor and privilege to be here with you this evening, an honor, privilege to follow Josh as well, who I look up to as my slightly shorter but more accomplished brother as director of our Gynecologic Oncology here at City of Hope, Orange County. And so my role is actually I'm a urogynecologist. I'm a urologist that specializes in pelvic floor reconstructive surgery and quality of life treatment for people who have gone through challenges that present in the pelvic floor.

And so we're going to talk about that today. What is the pelvic floor? And how can your quality of life be impacted and what we do to make it better? Briefly though, we're going to talk about survivorship and the concept of survivorship. So survivorship is a term that's really morphed. At one point we thought survivorship was someone who got through a diagnosis and survived their cancer.

I will tell you that whole concept is changing. And the term survivorship now is really morphing into what Dr. Josh Cohen has mentioned, which is chronic disease. It's a disease state where you are living through or living with a cancer process. And we are here to treat you and improve all aspects of your quality of life. But by all standards, the NCCN, which has been mentioned already by Josh, has a set of standards that large centers are subscribed to and we're included in that. And this is a whole litany of things, looking at how to make someone do really well for a really long time.

And so I won't go through that list, but it involves everything from surveillance, to screening to late-term effects of cancer treatment, whether that's immunotherapy, chemotherapy, radiation therapy, but it's really monitoring for all those effects and the impacts it can have on your day to day.

Really, the goal is to enhance quality of life through a multidisciplinary team approach. That means trying to address issues such as hot flashes, lymphedema, urinary incontinence, sexual dysfunction as Joan discussed, fatigue, pain, distress, mental health challenges. And this takes a team. This is not just one specialist, one physician. This is plastic surgeons, dermatologists, urogynecologists, urologists, gynecologic oncologists, and the list goes on and on. And in truth, it's also support for the caregivers as well. Really, that's a part of the survivorship program also.

What can you do to make your life better? These are some of the things that Josh touched on as well. If you're smoking, quit, cut down on alcohol consumption, a balanced diet, really the Mediterranean diet is the standard for that. And exercise and stay active. Now, let's talk a bit about the pelvic floor. What is the pelvic floor? The pelvic floor is your day-to-day.

It's going to the bathroom. It's voiding, fancy way of saying peeing. It's pooping. Fancy way, that's defecating. These are the things that we do on a day-to-day basis that we probably don't talk about with our friends and family, but unfortunately are really impacted by treatment for ovarian cancer and for other cancers of the urinary reproductive tract. And so we're going to briefly touch on four things. Urgency and frequency of urination, stress urinary incontinence, pelvic organ prolapse, and recurrent urinary tract infections. And these are all things I see day-to-day in the patients that I care for at City of Hope.

And so what do you need to know about the bladder? What is the bladder? It's actually an amazing organ. It's really a hollow muscle. That's really what the bladder is. It's a reservoir. It's a hollow muscle, and it's meant to store and empty urine at low pressures. So it's got nerves. The nerves control the function of the muscle. There's two sphincters in the bladder. There's an internal external sphincter, and the bladder is connected to the urethra. The urethra being that little tube that empties your bladder into the outside world.

And so like any muscle and nerve complex in your body can be impacted by various external stressors. Neuropathy matters. So as I said, the bladder has nerves, and so systemic therapies like chemotherapies and immunotherapies that impact nerves can impact the bladder, diabetes, Parkinson's, MS, spinal cord injury, all these things can impact the bladder when it comes to urgency and frequency urination, what does this mean? "Gosh, Dr. Cohen. I feel like I'm going to the bathroom all the time. I'm living in the bathroom. I feel like I always have to empty my bladder."

Well, there's some things we have to think about. Number one, we want to make sure you don't have a urinary tract infection. We ask about blood in the urine. Blood on the urine is something that has to be investigated. Sometimes cancers spread to the bladder unfortunately, and that could be a demonstration of what's going on. Lifestyle modifications. I have some patients come to see me and the first thing I say is, "Please cut down on the coffees and the teas." "I didn't know iced tea could make me go to the bathroom." It absolutely can. If you're someone enjoying those brisk iced teas four to six times a day, I've just changed your life. Cut down the iced tea. Okay?

Fluid intake is a little bit of an urban myth. Some people think you have to be drowned in fluids to live a happy, healthy life. That's really not true. There are some clinical circumstances like kidney stones where you want to drink a lot of fluids, but in general, most people can drink to thirst and be okay. The fact of the matter is the more you drink, the more you going to go to the bathroom. So if you're drinking liters and liters of fluid throughout the day, you're going to be going to the bathroom a lot.

Often you may be on a diuretic. If you're on a diuretic, try to talk to the physician managing your diuretic. Try not to have that in the evening. If someone's taking Lasix right before they go to bed, they're going to make a lot of urine and have to get up at night. So if you have a physician you're working with, try to take your diuretics earlier in the day. We have medications that can manage bladder spasms, often that urgency, urgency, frequency, sensation is a bladder spasm. It's that bladder muscle contracting and giving you that sensation you need to go. And there are medications that can absolutely help make a difference with those spasms.

Beta 3 adrenoreceptor agonists, anti-muscarinic medications, that's a whole topic unto itself, but please know they exist and you should ask your physician about them. And then pelvic floor physical therapy and biofeedback, and we'll touch on this a little bit more, but having a location to go do quality pelvic floor physical therapy can be very valuable. This is some information for your reference about pelvic floor physical therapy. There's a couple of good websites with some baseline information. There really is no replacement for doing this one-on-one with someone who has expertise in pelvic floor physical therapy.

Believe it or not, there are more advanced therapies for urgency and frequency and urgency incontinence, bladder Botox. Botox is not just for wrinkles of the forehead, it's also for bladder wrinkles. So we can actually inject Botox into the muscle of the bladder and partially paralyze your bladder and lessen bladder spasms.

Believe it or not, there's a pacemaker for the bladder. So there's a little pacemaker that can be installed in the lower back area that can send signals to the nerves of the pelvic floor and change the way you void or pee. And there's even acupuncture, otherwise known as posterior tibial nerve stimulation and we stimulate a nerve in your ankle that can also change the way your bladder functions. And all these are feasible technologies done in any advanced urology office.

Stress urinary incontinence. Let's shift. Sweet. We're just talking about bladder spasms, having that urge that need to go to the bathroom all the time. What's stress incontinence? Stress incontinence is leaking with activities. Coughing, sneezing, laughing, moving, lifting your grandchild. These are all things that can elicit incontinence if you are experiencing stress incontinence and there's therapies that can help with this.

Pelvic floor physical therapy is absolutely a part of that. Again, that'd be great for you to access if you had the opportunity to do so. These are actually vaginal inserts. Believe it or not, they're tampon-like inserts. You can get on Amazon or Target or Walmart.com tonight. You can order them. I suggest order the sizing kit because you're need to determine if you're a small, medium or large. And they expand in the vaginal canal to push up on the urethra and buttress the urethra and provide support. So there's less leakage with coughing, sneezing, laughing, moving. These are not right for everybody, depending upon your anatomy. But I've had some patients come and it could be such an easy game changer for someone if you're looking for situational improvement.

Bulking agents, fillers. So fillers are not just for wrinkles. Fillers are also for the urethra. And so we can take a small medication in a camera, look in the urethra and inject the urethra with this medication to bulk and fill the urethra, and we create more resistance at the level of the urethra, so you leak less with coughing, sneezing, laughing, moving. This can be done in an office setting. This could be done in a surgery center. It takes less than 20 minutes. And again, it can be a game changer. It can be a quality of life changer for you, and you can go from wearing pads constantly to wearing little to no pads.

There are some nuances. This is not a therapy that lasts forever. It's more of a transient therapy, maybe months to a few years, but still can have a significant improvement. Slings, maybe you've heard the word sling over the mahjong table. You've talked about it with your friends. What is a sling? A sling, the word is a euphemism for support. Essentially, you're providing a hammock of support to re-support the urethra. So when you cough, sneeze, laugh, jump, there's a buttress behind it that kind of keeps it co-active, so urine doesn't leak out. And these have been around for years, for decades. They could be made of synthetic material, otherwise known as mesh. They can also be made from tendon.

So we take tendons from thighs and we transfer the tendons underneath the urethra by making small incisions in the vaginal wall, so we can use your own native tissue to do this. This is quite amazing that it functions very, very well. We have patients going from diapers to once again wearing few to no pads for incontinence. So amazing interventions that can have significant quality of life improvements.

What is pelvic organ prolapse? Pelvic organ prolapse is a hernia of the pelvic floor. It's a hernia of the vaginal canal. So when someone says, "Gosh, I feel like something's coming out. I feel like something's pushing outside my vaginal canal, or I'm giving birth to a baby." Well, it probably is the vaginal wall that you're feeling. It's the vaginal wall that's thinned over time, usually in the setting of previous pregnancy and just maturity. I will say I've had women that have had no previous pregnancies come in. I've had nuns come in with pelvic organ prolapse. And so it can really happen to anyone. It's a connective tissue disorder.

And again, a significant quality of life issue. And you may feel something down there and it doesn't bother you at all, and that's okay. Some women come in and they're very bothered by that. Some women come in with advanced processes where they chafing or bleeding because the tissue is rubbing on their undergarment. And it can also impact voiding and defecation as well. There are lots of options for pelvic organ prolapse. So for instance, there's something called a pessary. Maybe you've heard of a pessary.

It's a silicone ring that can be placed in the vaginal canal to support the tissues and keep tissues inside. Again, physical therapy is an option, but there's also reconstructive pelvic floor surgeries. So for instance, this could potentially be combined with a gynecologic oncology surgery. If someone had an underlying diagnosis of uterine cancer and was experiencing pelvic organ prolapse at the same time, someone like Dr. Josh Cohen and myself could surgically work together to do all of that to address all of that in the same surgical setting. And that's really quite satisfying for us as surgeons and as medical professionals to really improve not only someone's quality of life, but address their cancer care as well, all at the same time.

Pelvic floor physical therapy. So once again, touching on that, I have some patients that come in and see me say, "Dr. Cohen, I do Kegels. I do the physical therapy. I know what that is." I have to tell you, it's not just Kegels. Kegels are just the tip of the iceberg, so to speak. There's really interesting names like pelvic brace, pelvic tilt, deep squat, lateral lunge, inner thigh squeeze, bridge with knee taps, clamshell, prone diamond. These are all different exercises that you can learn with your pelvic floor physical therapist and do on a regular basis.

And I am so impressed when people come to see me, and honestly, it can be just this that takes them from being depressed, unhappy, impacted to being significantly improved, engaged, energized, and socializing. There's a lot of different pelvic floor physical therapy options out there. So I want to highlight Hinge Health. Hinge Health, believe it or not, is a really unique platform. It's remote pelvic floor physical therapy. So some of you may live in locations where you don't have access to physical therapy or you can't go see someone or leave the house. This actually is an app and a website where they can work remotely with you as best they can to teach you pelvic floor physical therapy exercises.

So if there's an opportunity to engage with that, I would encourage that. I think some of the best ways to do this is in person one-on-one. Often these are found either at NCCN Comprehensive care, Cancer Centers, or perhaps at a local physical therapy rehabilitation facility. Be a little wary. Sometimes people will tell me, "Oh, I go do my elbow physical therapy over at you know, it's across the street from my house. It's fabulous. They have this there, right?" No, they don't. It's very different from orthopedic physical therapy. So just because a place has orthopedic physical therapy, it's not absolutely a given they're going to have pelvic floor physical therapy.

Recurrent urinary tract infections, we're going to touch on briefly. I just want to highlight that recurrent urinary tract infections can be devastating. They can leave someone chronically in pain with burning with urination, feeling like they're on antibiotics all the time, in and out of urgent cares, in and out of ERs on a cyclical wheel of antibiotics. There are guidelines to help with this. The American Urologic Association has a set of guidelines regarding your current urinary tract infections, and this is a foundation for treatment. It's not the whole answer, but it's a foundation. So I would encourage you, if you're suffering with recurrent urinary tract infections, please see a urologist, urogynecologist specialist because they can absolutely improve your quality of life more than just an infectious disease doctor, more than just a medical oncologist or gynecologic oncologist.

They're all fabulous, but there's really no substitute for having a specialist in the urinary tract engage with this and really try to guide you and help you. What do I do? I talk about prophylaxis. I talk about prevention. One of the things I really also will experience is when a patient comes in with a stack of about 42 pages of all their urine cultures from the last year, and they put it down on the desk and say, "Dr. Cohen, here's my urine cultures. What are you going to do?" And honestly, I put that to the side. That doesn't change my discussion with them much at all. To be quite frank with you, because I focus on prophylaxis, prevention of UTIs, that's where we can succeed.

The urine grows out everything. It's a Petri dish. So what you grew in the past doesn't absolutely matter. What matters is preventing UTIs, and there's a regimen we can use for that. So Methenamine, for instance, that's a prescription medication I can give you. You take twice a day. It changes the pH of your urine. And bacteria don't like to live in the urine as much.

Some caveats to that, but that's something we can offer as a prophylaxis. Cranberry, there's debate about cranberry. For me, I use it in my practice, but it has to be a high quality product. 36 milligrams of proanthocyanidins, PACS, P-A-C-S. That really is what you want in a high quality cranberry product if it's going to help you reduce the risk of urinary tract infections. Vaginal moisturizer, now this leads into a little bit of the topic that Joan was mentioning. A very important topic about sexual health and quality of life with pelvic floor. And vaginal dryness and irritation, again, could be devastating, the setting of the treatment of these disease states, reproductive cancers.

And so there are vaginal moisturizers out there that do not have hormone products in them, that are safe for you to use. There are vaginal lubricants that are out there that are safe for you to use. And often when these are combined with occupational therapists where they can train you in utilizing vaginal dilators to keep the anatomy functional, keep length and width functional within your vaginal canal, you can continue to have a very, very appropriate and hopefully very satisfying quality of life.

Bowel movement regulation. So if you're having diarrhea, guess what? You're at high risk for UTIs. So all patients will come in to see me and I ask their bowel movements, and I'm saying, "Well, are you having loose bowel movements? All the time. Well, we know that's why they're getting UTIs, right? So fecal reservoir, that's where the bacteria come from. And so after bowel movements, if you're debilitated, frail, having loose bowel movements, first of all, try to address loose bowel movements with your oncology team or with your primary care team.

There may be ways to do that or a gastroenterologist, but think about perineal care. What is perineal care? It is cleansing the bicycle seat area. If you use the word, perineum or perineal with your medical provider, they're going to be super impressed. But basically all it really means is cleansing the skin between the rectum and the vagina, that bicycle seat area.

There's a few different ways you can do that. You can do that with a spray bottle of soap and water. You can do that with some wipes, although I don't love the wipes. I think something I really like for patients is a toilet top bidet. So maybe you've heard of the word bidet. Often it brings in thoughts of hundreds of dollars on a new toilet, you can get a toilet top bidet for $75 online, maybe less. We have one in my house. It works very well.

And this bidet really the main function is to help you cleanse that skin between the rectum and the vagina to really cleanse that area so there's not fecal debris on that area. And once again, reduce the risk of a symptomatic urinary tract infection. This is just an example of what my patients will do. We put them on a regimen. We ask them to call us if they have UTI symptoms. We have them come into the office. We do a catheterized urine specimen. What does that mean? We take a small catheter, we drain their bladder in the office. Why? Because 20 to 30% of the time you pee into a cup is contaminated, especially if the anatomy such where the meatus is high up inside the vaginal canal. Also, if you're frail and debilitated, it's hard to believe you're going to be able to catch the urine in a cup.

And so we want to help you and we do a small catheterization to collect the urine. We put them on a short course of antibiotics while the urine culture is pending, and then we confirm they've been given appropriate antibiotics based on the susceptibilities. There are some other things we offer patients like post-coital antibiotics, if they're noticing intercourse is a trigger for urinary tract infections. Sometimes we'll put patients on daily antibiotics, although it's really rare. I try to avoid that to be honest with you, because I want to keep your microbiome intact. Your microbiome is part of your body. It's good bacteria. I don't want to kill the good bacteria by having you on antibiotics all the time.

And then of course, there are patients in need, the involvement of multidisciplinary team members, including infectious disease specialists. And so I want to bring that to inclusion. I want to thank Sharsheret very much for being a part of this extraordinarily meaningful and important organization. It's a true honor and privilege to care for you and to be a part of this care and to partner with Josh. I'm just grateful to really help in any way I can. Thank you very much.

Jenna Fields:

Thank you so much Seth for that wonderful presentation. I learned so much. And now we're going to jump into our Q&A. So I'm going to ask for both brothers back on the screen. I'm going to use your first names just so we don't get confused about which Cohen. And I'm just going to start with the questions that have already been entered in the chat, and then we'll go to the one submitted in advance. So Josh, I think this is a question for you, but what does the research say about estrogen blockers used for estrogen receptor cancer for ovarian cancer?

Dr. Josh Cohen:

And there is good data for the use of estrogen receptor blockers. It depends a little bit on the type of ovarian cancer. I mentioned the term serous cancer. There's high grade and low grade. So low grade serous cancer is a tumor subtype where we really do take advantage of hormonal blockade to treat or help reduce the risk of this cancer coming back. And so there is a role for it. For someone who has high grade serous cancer, if we were going to use a single agent hormonal blocker, an example is something called Anastrozole or Letrozole, which is an aromatase inhibitor more commonly used in breast cancer.

The response rates by themselves are probably going to be about 10 to 12%, give or take. But we are now combining these hormonal medications with the immunotherapy drugs that we have available. There is something called CDK4/6 inhibitors. An example is Palbociclib or Ribociclib. So combining that drug with an aromatase inhibitor, we can see a much higher response rate. So the answer, it does have a role, it's not for everybody. The response rates are going to be overall a little bit lower than other treatment options, but it's really a great option for patients who want to take a treatment that has less side effects because we know the hormonal therapy options do have much less side effects than other treatments, but the response rates are also a little bit lower.

Jenna Fields:

Okay. Anything new to address cancers caused by CHEK2, the I157T variant.

Dr. Josh Cohen:

So CHEK2 is a mutation that we are actively studying. We know that it does play a role in the development of cancer. There's not a specific drug that targets the CHEK2 mutation that we're using in ovarian cancer. But as I mentioned, PARP inhibitors, we would want to do a genetic analysis. And patients with CHEK2 certainly are going to likely be good candidates for PARP inhibitors unless there are other restrictions. And so we do have tools in our trade to focus on that mutation. It's also important to reduce the risk of other cancers with patients who have CHEK2. So seeing your doctor for screening for other cancers and then talking to your family members to make sure they get tested. But there's not a specific drug that targets CHEK2 itself right now for ovarian and fallopian tube cancer.

Jenna Fields:

In regards to someone who's not a candidate for HIPEC, why isn't IP chemotherapy offered more often?

Dr. Josh Cohen:

So IP chemotherapy has been thoroughly studied. It's still used in the upfront setting for certain populations. We know that it has challenges. Having a port placed in your abdomen and then coming back every three weeks to get your abdomen filled with chemotherapy is not easy to do for anybody. And it's really hard to do for the staff. So to be honest, it's fallen by the wayside a little bit because patients really didn't like it. Their quality of life suffered and the staff didn't like it, the medical oncologists had trouble doing this for patients. It often required hospitalization or hydration.

There was a clinical trial then called GOG 252. GOG 252 looked at intraperitoneal chemotherapy as compared to IV chemotherapy, and they added that medication called Avastin or Bevacizumab to all the regimens. And when you added Avastin to all the regimens, all the regimens did just the same. So that was kind of the nail in the coffin that for everybody who didn't want to do IP chemo, they said, "Well, this is it. We're just going to give people Avastin or Bevacizumab in addition to IP chemo, and they're going to do just as well as those who would've had the IP chemo but less toxic."

That being said, HIPEC is a good option for patients in the upfront setting. So I would encourage you to talk to your provider. It's not for everybody. It's for patients who have stage three cancer who are getting chemotherapy first or neoadjuvant chemo, but IP chemotherapy is still out there. It's hard to do. And the data says that it's probably equivalent if you add this medication called Bevacizumab.

Jenna Fields:

Seth, you use the word survivorship a lot, but do you ever use the word cure when talking about cancer with your patients?

Dr. Seth Cohen:

I personally don't like the word, cure. I think survivorship to me means the most, whether or not you're cured or not, you're still a living, breathing person. You still want the same things. You still want to have the best day-to-day you possibly can. And so the word, cure, I leave to people like Josh, whether or not that's feasible or not. Actually, when patients come to see me, I actually just ask them, "How's the cancer cure going?" Okay. And then we move on to their quality of life discussion.

In general, I try not to focus on the state of their cancer. I try to focus on them as a human being, the Malady, the challenge they're experiencing. We try to address it as much we can. Whether they're coming to me almost at the end of their journey, in the middle of the journey, beginning of the journey, it makes no difference. We're focusing on improving their quality of life to the best we possibly can.

Jenna Fields:

Do you both have a good recommendation? You spoke so highly about finding comprehensive cancer centers for your treatment and also using survivorship. Do you have a recommendation for patients who are looking for more comprehensive programs at NCI designated hospitals?

Dr. Josh Cohen:

Yeah. If you go to NCCN.org and look, it'll give you a list of NCCN Cancer Centers across the country. There are about probably 50 of them. And many of them will take all insurances. There are some exceptions, like if you have Kaiser insurance, you are limited to Kaiser institutions, which are not NCCN cancer centers. But outside of that, you should be able to get to one or even do a telemedicine with one. And it is just a cancer center that meets a number of requirements that we know you're going to get the level of care that we would want for you.

Another really good website clinicaltrials.gov. Clinicaltrials.gov is a federal government funded website. Any clinical trial that's available, if you type in ovarian cancer on clinicaltrials.gov. You're going to find a trial and it'll tell you where it's available. The third most important website is Sharsheret's website. And I would say you could move those around any way you want, but all those are really important websites. So clinicaltrials.gov, Sharsheret's website, and also NCCN.org.

Jenna Fields:

And you didn't even attend our ambassador training, Josh. Thank you. Okay, last question because I know we're running out of time, and then we're going to move on to our Embrace Breakout in a minute. How's the AOH1996 trial coming along and do you see it as the real game changer that's available soon?

Dr. Josh Cohen:

Thank you for asking. AOH1996 is an exciting drug. It got a lot of press because it's a first in class drug. It's a new way to attack cancer cells, but it's an extremely early drug. So the trial that was done, you had to take 40 pills a day to be in that trial. So to ingest 40 pills a day as a law for any human being, it wasn't looking at efficacy, meaning it wasn't looking at how well the cancer responded. It was looking at how patients responded.

Did they tolerate the drug? Did the drug impact their kidneys? Did it impact their heart? So it was more of a feasibility study. We are extremely excited about it at City of Hope. It's still extremely early. It's going to be sometime before that drug makes it to what I would say a standard of care for patients. But again, we're really excited about a lot of treatments, not just that drug, but a lot of them, but that drug's very, very early.

Jenna Fields:

I really want to thank you both, and I know there's more questions we didn't get to, but want to stick to time. So thank you both for your incredible presentations. We're going to put an evaluation survey in the chat box now so that everyone can send us an evaluation and we can continue to offer more programs targeting our ovarian cancer community and addressing the needs that you have. Please never forget that Sharsheret is for you wherever you're at in your journey. And please don't hesitate to contact us if you need any support or resources.

Just a reminder that this is part of our Sharsheret Summit Kickoff, which is officially October 9th through November 10th. So please take a look at our upcoming Sharsheret Summit webinars and register yourself for as many as you want. We're grateful to our sponsors, GSK and Immunogen. And thank you to our Sharsheret sponsors, our summit sponsors, AstraZeneca, Daiichi Sankyo, Merck, Pfizer City of Hope, Orange County, Eisai, Northwell Health Cancer Institute, and RMA of New York and Long Island.

And at this time, as you're filling out the evaluation, I ask that folks sign off except for those who are part of our Embrace community. That's our community of people facing advanced or recurrent ovarian cancer. So thank you again, Dr. Seth Cohen and Dr. Josh Cohen for your expertise. Thank you everyone who joined us this evening. And we'll just wait a moment to start our Embrace Breakout together as folks are logging off. So thank you again, everybody.