From Diagnosis to Dignity: LGBTQ+ Lives and Cancer Care

National Webinar Transcript

June 23, 2025

Presented by:

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community

This program was made possible with support by:

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The Cooperative Agreement DP24-0061 from the Centers for Disease Control and Prevention

About Sharsheret

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

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

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

Sharsheret offers the following national programs:

The Link Program

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

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

Education and Outreach Programs

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

Disclaimer

Jenna Fields: Welcome. Thank you so much for joining us tonight for our webinar. I'm Jenna Fields, I'm Sharsheret's Chief Regional Officer, and my pronouns are she/her, and this evening's topic, From Diagnosis to Dignity: LGBTQ+ Lives and Cancer Care, is such an important one.

I want to take a moment to thank our sponsors for the program. Thank you to the Basser Center for BRCA, Cedars-Sinai, Genentech, Novartis, and the Cooperative Agreement 24-0061 of the Centers for Disease Control and Prevention. And I want to thank our community partners who are listed on the slide for their support. That includes Beth Torah Benny Rok Campus, Congregation Ahavath Chesed, Congregation Shaare Emeth, Eshel, IKAR, JQ International, Keshet, SOJOURN, SVARA, Temple Beth-El of Northbrook, Temple Sinai of Hollywood, and Temple Sinai of North Dade.

Just a few housekeeping items. Tonight's webinar is being recorded and will be posted on Sharsheret's website along with a transcript in the coming days, and participants faces and names will not be in the recording. However, if you want to remain private, please follow the instructions in the chat box. My colleagues are putting it in the chat now, and we also have closed captioning available and that information is in the chat as well.

You may have noticed that you were muted upon entry into Zoom. Please stay muted during the call. We are going to have a Q&A following our presenters presentations. Please type that information into the chat box as we're going. I'll monitor the Q&A, and then we'll get to your questions, as many questions as we can, after they're finished speaking.

And as you know, Sharsheret is a national not-for-profit support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret and tonight's speakers 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. If you have any questions that are specific to your medical care, always seek the advice of your physician or qualified healthcare provider.

And before we begin, I just want to acknowledge how difficult things have been recently both in Israel and also in the United States, and our hopes and prayers and wishes go to everyone who's experiencing feelings of worry and fear, including those in the LGBTQ+ community. Our hearts are truly with everyone.

And now it's my pleasure to move into this really important webinar we're doing tonight. I'm so grateful to all of our speakers who are joining us. We're going to start tonight with two cancer thrivers who are going to share their personal stories. And first, I'm going to welcome Sandra Chefitz who's going to join us right now. Sandra, we're going to spotlight you, and Sandra is a Sharsheret program participant. She's vice president at Munich Re North America Life. She and her wife, Marian, split their time between Brooklyn and upstate New York.

Welcome Sandra, and thank you so much for being here.

Sandra Chefitz: Thank you so much for having me and for facilitating the conversation.

I was diagnosed with breast cancer at 45 at the end of 2022, and just a quick plug for Sharsheret to kick off. I found out I had cancer through MyChart, which is not uncommon, and I was obviously overwhelmed with fear about what treatment was going to look like. My mom told me about Sharsheret and I reached out and I heard back within a day and I will always be grateful for that.

Marian, my wife, has been as involved as I want her to be at every stage. I tell people that one of the upsides to a same-sex relationship when you're navigating medical bureaucracy is that I've never had to make a phone call to a doctor, an insurer, a pharmacist. Marian impersonates me on the phone and she's sparing me so much of the administrative overhead of cancer treatment. She saved my time, she spared me the frustration, and my advice to anyone is if you can enlist people to do the same for you, it's going to make a huge difference in managing some of the smaller daily stressors.

It's common for women to grieve the loss of traditional femininity during and after cancer treatment. As a lesbian, a unique challenge might be this continuous reflection of your losses. So I've lost most of my hair twice now and it's hard to watch Marian blow dry and style her hair and even brush it when I'm preoccupied with all of the daily rituals to try to keep mine. And we're exactly the same age, but I feel a lot older than she is now with night sweats and leg cramps and fatigue and memory issues. I'm in menopause and she is not, and I'm reminded of that every time I open the cupboard.

At the same time, I don't think anyone could understand all the things that I've lost and how difficult the last couple of years has been as much as she can. She's a woman. She's the daughter of a two-time breast cancer survivor, and she's the most empathetic person I've ever met.

I was diagnosed about four months after I lost my father to cancer quickly. So I started the process with probably a healthier mistrust of doctors, and I'm sorry about the doctors that are here, than most people, but doctors are human and they're overworked and they can't allocate enough attention to all of their patients. And if you're not the kind of person that just goes along with the plan without questions, you're inevitably going to face challenges in getting your needs met during treatment. I had questions at every step and I asked for things that definitely weren't unusual but weren't protocol on the assembly line of care that I was moving across. I was well-informed. I did a lot of research and it was very difficult to obtain access to tests or medications that I asked for, to get the right follow-ups to manage side effects, and to convince my providers that I know my body better than they do.

Someone on a podcast observed that if you're hiring a contractor you get multiple quotes, but many people get just one oncology opinion. This is your life. Try to find someone who listens and who understands your priorities if not your values, and do your own research. A lot of what's helped me better manage short and long-term side effects I found through my own research and then I asked for, either from my oncologist or my primary care physician or gynecologist. Treatment can leave you kind of broken, and it hasn't been my experience that your oncology team is going to be active in helping to put you back together, and that's just not their job. You have to take the initiative and enlist support from other medical professionals.

And then last, don't worry about being liked. Again, this is your life. You're hiring a doctor to treat your cancer and not be your friend. Be as assertive as you need to be.

Jenna Fields: Thank you so much, Sandra, for sharing your personal story. It brings so much to this conversation and we're grateful you're here today.

Sandra Chefitz: Thank you.

Jenna Fields: It's now my pleasure to introduce Gabriel Glissmeyer who holds a Master's of public health and is a longtime LGBTQ+ health professional with a background in tobacco prevention, oncology, and HIV. As a transgender adoptee, Gabriel has had to navigate a family history of cancer while being confronted with a healthcare system not built for transgender people or adoptees. Fueled by his own adverse experiences with healthcare and public health systems, he has used this as a springboard to create national programming, educate healthcare providers and public health workers, and bring awareness to equity issues.

Welcome, Gabriel.

Gabriel Glissme...: Thanks for having me. I'm super happy to chat about my experience through the healthcare system as a transperson.

So one of my main concerns as a transperson was ultimately that I would find out that either I'm at risk or get diagnosed with a cancer that was exacerbated by hormone therapy. So after having had top surgery, I wasn't really concerned about breast cancer, but I was unsure about what it could potentially mean to have to pause or stop transitioning altogether and how I would potentially cope with that really difficult reality.

So I was adopted, and when Ohio opened up their adoption records about nine years ago, I learned about a very aggressive ovarian cancer that was in my family and I let my providers know, and they said, "We'll worry about it when your mom gets it or you have a sister that gets it." And so by 2019, my birth mom was diagnosed and died from the cancer. And in the middle of 2020, I had a pretty drastic change in health, and by the next day, I was scheduling surgery and being sent resources about hereditary cancer.

So navigating the system, aside from not having any family medical history until my mid-20s, the biggest challenge I faced was how many misgendering hoops I had to jump through to prove to the insurance company why someone who is listed as male for gender and sex on pretty much everything would possibly need to have gynecological organs removed. Another area of misgendering that I experienced was actually in genetic testing. So despite all of my medical charts listing my gender and my sex as male, pretty much to do my genetic testing, they had to list me as female to have it all make sense.

So for anyone who has clients or patients who are trans who are previvors or are concerned about cancer in their family, just know that the testing actually can be very triggering to trans patients or clients, as it can place them specifically in a male box or a female box, and obviously that might not match their gender identity. But I was very lucky to have a lot of very trans-affirming providers and surgeons in Utah who let me use back doors to get into the exam rooms instead of needing to sit in the very, very pink waiting rooms in the women's centers, basically advised me to ignore the very gendered language in all the ovarian cancer pamphlets that I had, and basically told me to let them know immediately if anyone from the front desk staff to ultrasound tech said anything negative about transpeople in front of me.

I've been very lucky in that way, so I haven't delayed or avoided appointments because of transphobia or how I would perceive to be treated as a transperson, but I definitely, I'm willing to admit this, I have avoided things like pap smears because, one, I only ever saw them advertised for women. And two, I also knew that they would be very, very uncomfortable as someone who has been on a hormone for a very, very long time. So in that case, it was really helpful to have providers who were so trans-affirming who could explain everything in detail, and we're really forthcoming with ways to minimize that discomfort, like prescribing me with mild sedatives during my pre-op, post-op, and also during my transvaginal ultrasounds that I had to do.

So as far as my tips and tricks for self-advocacy for other LGBT folks who are at high risk, honestly, just be sure to voice any concerns that you have with your providers, especially around any preventative services because those are so important on this journey. If you're worried about discomfort or not sure about what a procedure is, just let them know. They want to help you. And then reaching out to organizations like Sharsheret and talking through some of your options for support and connecting to other LGBT folks who have gone through similar situations because it's really hard to carry this alone and you really shouldn't have to carry this alone.

Jenna Fields: Thank you so much, Gabriel. Your experience is so enlightening and really important and we appreciate you being here this evening.

Now we're honored to have Alex Trifonov with us this evening. Alex is the program coordinator for the LGBTQ+ Cancer Care & Research Program at Perlmutter Cancer Center at NYU Langone Health. In this role, he actively navigates and advocates for patients across the cancer continuum from screening to diagnosis, treatment, and survivorship with an LGBTQ+ proficient framework. He holds a master of biomedical sciences from Rutgers, and his work spans patient advocacy, staff education, community engagement and health equity research with a focus on drivers of health and LGBTQ+ communities, including LGBTQ+ immigrants.

Now, as a reminder, if you have any questions, please put them into the chat or privately message me and we'll save them for the Q&A following Alex's presentation. And now I'm happy to welcome Alex to the screen now.

Alexandr Trifon...: Thank you very much, Jenna. It is my pleasure to be here. My name is Alex Trifonov. My pronouns are he/him, and I'm a program coordinator for the LGBTQ+ Cancer Care & Research Program at Perlmutter Cancer Center at NYU Langone in the heart of New York City.

So 50% of my job is active patient navigation and patient advocacy for LGBTQ+ folks within the cancer continuum and the non-cancer continuum, even when we have to do some screening and prevention. And as you probably could have guessed from my last name, I also speak Russian. I'm originally from Uzbekistan, so I do have a big population of Russian-speaking LGBTQ+ refugees from all post-Soviet Union countries that come to the United States and seek asylum and refuge and also need lots of services as they come to the U.S.

Let me just share my slides first and please let me know if you can see them. Yep. Great. Alrighty.

Everyone should know this, right? Cancer knows no gender. If you have it, please screen it. The very big focus that we do here at NYU Langone is, and more specifically at Perlmutter Cancer Center, we do “organ inventory” on all of our patients. So if we have, doesn't matter of gender identity, doesn't matter of sexual orientation of a patient, we do ask those questions as well, and sex assigned at birth, we do ask patients of what organs do they still have or what organs have augmented or removed. So we wanted to make sure that you get all the screening and prevention services depending on what organs you have.

Let's dive in a little bit in LGBTQ+ health disparities in general. Well, we all know this, but why do they exist? It's because of the discrimination, prejudice, stigma and other negative factors in a society, and minority stress. You all know that as well. So because of all of this negative impacts from the society, the community have higher rates of tobacco, vaping, alcohol, substance use, they get denied care, they have eating disorders, anxiety, depression, and unfortunately suicide. So the rates are, in LGBTQ+ communities specifically, are higher for all of those categories that I've just mentioned.

How about cancer-wise, right? We have overall health disparities. Now we're going in another layer of cancer. So what did it lead to? First, very, very big one, is lower cancer screening rates. That's what we care as number one priority for anyone who we talk to or I do the intake as a patient navigator. The first thing I go over in my brain's checklist of what cancer screening and prevention services they need to do. It also leads to a higher incidence of cancer diagnosis. At Perlmutter Cancer Center, we do see that LGBTQ+ folks come to us with a later stage of cancer. That's more research needed, but that's what we know so far.

Statistics-wise, this is national statistics. We're not talking just New York City. About 81,000 LGBTQ+ folks will be diagnosed with cancer each year. This is really sad. And some going more into identities and sexual orientations. We have lesbian and bisexual women are 2.0 to 2.3 times more likely to receive any cancer diagnosis. Gay men are at increased risk of anal, prostate, and HIV-associated cancer, and are diagnosed at a younger age. And transgender and gender-diverse folks are 2.3 to 3.0 times more likely to have infection in those cancers. And I will explain what the infection in those cancers mean in a little bit.

What we don't know, the incidence per cancer type. We don't know how many LGBTQ+ folks get cancer in certain disease group, like let's say breast or chest cancer. We do know somewhat from the statistics, but we don't know the accurate number just because folks are just not comfortable sharing their identity. We are lucky to be in the heart of New York City, so lots more patients are open. And I would like to recognize that in parts of the country, there are places that LGBTQ+ folks are not as open or the healthcare is not as great as here.

And also, what we don't know is cancer-related data in racial and ethnic LGBTQ+ minorities. There's not enough data, but it's still an issue. We know that health disparities are layered. There are layers of health disparities. There's a LGBTQ+ minoritized group, and there's also racial and ethnic minorities. If we combine those two, then the health disparities get even worse. So, we need more data in that field as well.

But why is there not enough information? So we all know there's not enough, but why and what can we do? So A, underreporting or non-collection of sexual orientation gender identity, or as we call it, SOGI, or some people call it SOGI, and across the nation, which is challenging. And again, that goes towards recognition being in New York City or versus another state or a city within the United States where the healthcare is not as accessible for the LGBTQ+ folks. Not having an LGBTQ+ proficient clinician, and you deserve one. Everyone deserves a proficient clinician that is proficient in your care and your health needs. So please advocate for yourself or have folks who can advocate for you or find navigators and advocates that can possibly help you to make this as the first step. And I am talking about not just primary care, oncology, GYN, urology or anything like that, even orthopedic surgery. As we can say, it's not cancer-related, but even in any specialty, that really matters, right?

So LGBTQ+ folks are avoiding disclosure of SOGI and sexual practice information due to, obviously, stigma, prejudice, and other negative factors. And social drivers of health or social determinants of health are affected. We're talking about housing, jobs, mental health, environmental factors, schools, mental health resources, and other things.

And cancer prevention-wise, so I love my focus on cancer prevention, and if you can prevent it, that's amazing and you have a much better chances if we catch it to treat it and cure it. So why LGBTQ+ folks are less likely to undergo cancer prevention and screening services, A, not having health insurance. That's a big thing. Gendering of cancer screening. And Gabriel, thank you so much for saying that about being in a facility when you're given a pink gown, a pink brochure, when you're being a trans man or someone from other gender identity that is not a cis woman or a trans woman or any other identity.

So lack of the primary care clinician who is proficient in your care, previous negative experiences. If you had a negative experience, you're less likely to go for the same service when you need it again. And I'm talking about specifically, also like Gabriel mentioned, and thank you so much for saying that, pap smear for trans men. This can be highly traumatizing. That's why we need to make sure we have a GYN or a PCP who can definitely take care of that in a very proficient manner, in a very comfortable manner, and listen to the patient and acknowledge what patient wants.

Obviously, patients and there's a clinical lack of knowledge in healthcare and how to screen for certain cancers specifically, which we're going to dive deep in a little bit. And denied care by clinicians, that unfortunately still happens. We wish it could be different, but it does happen unfortunately.

So how to prevent cancer, a big question, right? So in general, what can we do is obviously you're going to go to your primary care physician or your primary care physician will mention those four categories, what can you do. Healthy eating, exercising, reducing tobacco use and vaping, reducing alcohol intake. Even if you do one of those, you're already reducing the cancer chance for yourself, any cancer we're talking about. So the more you do, obviously the better, and there is help that is available for each of those categories. And again, the city where I provide my services in, we do have lots of services, so for people who's like, "I can't find this service," mm-mm, there is a possibility. Obviously for some folks, it could be much more difficult, and again, I wanted to recognize that as well again.

Infection prevention. HPV or human papillomavirus, as simple as you can get, a series of three vaccines. And I do like to ask this question at all my community outreach and educational events and I asked the community, I was like, "So who should get an HPV vaccine?" And they're like, "Everyone, the answer is everyone." Obviously, there's certain age restrictions, but everyone needs to get HPV vaccine. No matter of your gender identity, sexual orientation, sex assigned at birth, none of that matters. Everyone needs to get it.

Hepatitis B, hepatitis C, obviously hepatitis B, again, we can give vaccination. Hep C, there's no vaccination, but we can do blood work. We can keep checking for that. And if, unfortunately, if you have happened to receive diagnosis sooner, that's better. You can treat it and cure it, and it is curable now, so please get tested.

And then H. Pylori, we know that if you have some certain symptoms and like acid reflux or anything, don't ignore it. Go see you gastro and have them test you for H. Pylori, and if you do, please get treated because throughout some time, it can cause stomach cancer. It has a very high chance for that.

And HIV, again, if you don't have a diagnosis, there are PrEP and PEP options available. PrEP is to prevent HIV and PEP is post-exposure prophylaxis. So if you had a contact and you happened not to taking PrEP, then you can take PEP. But it is preventable, so there are resources. And if you do have a diagnosis of HIV, there are also a bunch of medications available that they can take and they can help control it. And if you are controlling HIV, I know people, there are some studies before that the physicians like to mention this, someone who has an HIV and has it controlled have the same life expectancy as the person who doesn't have an HIV. Just keep that in mind.

And this is the big one. Find LGBTQ+ proficient clinician and/or service. Once again, I think I'm saying it for the sixth time already, it is important to find one, but I do want to recognize that it's difficult for some folks. If you need something, just ask. I mean, even if you don't know anyone and if it's problematic in your area, just reach out to someone even outside of your area. They might have colleagues. I mean, I do talk on my personal experience, for example. We all communicate throughout the country, and if you haven't heard someone, maybe I've heard someone who has in Oklahoma who provides such care. So just ask no matter who, and if you know this person knows someone, they'll be amazing.

All right. Let's dive in into screening guidelines. There's lots of info on those slides. I'm just going to simplify it and we can definitely send those slides to everyone who's registered later and I'm happy to share them, obviously.

So for breast and chest cancer screening, again, if you have it, screen it. And the reason why I'm listing here gender identities, you can be like, "But you just said if you have it, screen it." Some factors matter. So the National American Cancer Society guidelines for breast/chest cancer screening say you have to do annual mammogram starting at age 45 until 75. That's the standard guidelines. They didn't even mention cis women, trans women, they just say, "Just women." Those are someone who was born as a woman.

So for transgender women, we have if this person is 50+ and have a 5+ year of hormone therapy, then they need mammogram every two years. Or trans men, depending on anatomy, if the chest masculinization was done, there could be some residual tissue still there. This is very important to know. Chest masculinization does not equal typical mastectomy for breast cancer, so some mammary gland tissue gets left behind so you need to make sure you screen that tissue for cancer. Obviously, if you have some family history or genetic history, it's much more earlier and then you have do testing and possibly get screening much earlier, like MRI, for example, specifically from trans men, I'm talking about.

For cis women, national guidelines. For cis men, there's no recommendation unless symptomatic or significant family or genetic history. And then other identities, again, organ-based approach and status of taking gender-affirming medications.

Now, cervical cancer screening, anyone who has cervix. Again, no identity, anyone who has cervix. So national guidelines from ACS, again, tell us the start of age of 25 and pap test every three to five years, and HPV co-testing or human papillomavirus co-testing. Again, if you need it sooner, your physician will tell you depending on the result. But if it's negative, an HPV is negative, three to five years. That's the usual guideline.

For trans women, no screening because, again, there's no cervix and there's no surgery to a men's cervix, so there's no need for screening. But again, if there are some HPV-related lesions in neovagina, if someone had a vaginoplasty and they had a reconstructed neovagina, then they need some HPV screening on that. And this is very detailed, so that's kind of you have to discuss with your physician.

For trans men, if cervix is present but if on testosterone should definitely be indicated on a report or on the order that the person is taking testosterone because that will affect cytology or cells on the sample, so that needs to be mentioned and differentially diagnosed by a pathologist when they're looking at the sample. Again, increased risks of abnormal testosterone, that's what I just said. And no screening of services removed and there's no history of high-grade lesions.

Cis women, national guidelines. Cis men, no screening, no cervix. And other identities, again, organ-based approach.

Uterine/endometrial cancer screening, no recommendations from ACS, but for trans women, no uterus or no endometrium, no screening. For trans men and other identities, also no screening, but if uterus is present and there's unexplained genital bleeding, then it needs to be evaluated and also screened for cancer.

Ovarian cancer, no recommendations, again, from ACS, official ones. And there's for trans women, no screening because no ovaries. For trans men and other identities, also no screening. Guidelines, we're talking about. But if there are ovaries and there's significant family history of breast and/or ovarian cancer, then they may require genetic counseling and further testing.

Anal cancer screening, this is a newer cancer screening test that we were spreading the word about and people started thinking about it. People don't know much about it, even in New York City. I was just doing it at Brooklyn Pride. We had a Brooklyn Pride on the 14th and I tabled there, and I was just asking people in the community, I'm like, "Do you know what anal pap is?" They're like, "Eh, no." I was like... I think I only had two people who actually said that they know what anal PAP is.

There is a test for anal cancer screening, and I'll explain it in a little bit. No official recommendations from ACS. We have the beautiful ANCHOR Study that tells you how to screen, and from IANS International Anal Neoplasia Society, that also tells us the guidelines for that based on research. So typically, we have high-risk population, medium-risk population, low-risk population. So high-risk population is someone who's over 35 and HIV-positive, men who have sex with men or transgender women. I just say in general, 35+ with the HIV+. So that's it, no matter of identity. But then we do anal pap every one to three years depending on the result.

So anal pap, like a cervical pap smear, but it's from anus. You take a sample with HPV co-testing ideally, then you screen it, and if it's negative both, then doctor will tell you in a year from one to three years. And if it's positive, then they go for basically same thing as colposcopy for cervix, but it's called HRA, or high-resolution anoscopy. It's basically looking at the cells of anus in real time using a microscope.

Some, for example, at NYU we just launched a new program, so we have it ambulatorily now, it used to be in the OR which is catheter, anesthesia, a day off. So it's like someone needs to pick you up or whatever, but now it's done ambulatorily so you can just come and get it done. And if you need a biopsy, they will do the biopsy there as well.

That's for anal cancer for 35+, HIV+. And someone who's 45+, HIV-negative folks and other HIV-positive population, and if someone who is 10+ years in solid organ transplant, and someone who had vulvar or cervical dysplasia, especially HPV-positive dysplasias. So if anyone who has cervix had dysplasias and HPV-positive, they also should be screened for anal cancer because of their very close proximity anatomically.

Colorectal. For all LGBTQ+ community members, we should say 45 to 75. 45, that's the standard screening age. Again, the gold standard is colonoscopy. I don't know who does sigmoidoscopy anymore, but I had to put it there because that's the guideline, or stool-based test. So colonoscopy is a longer camera and sigmoidoscopy just screens the lower parts of colon and sigmoid colon. That's the difference. And again, if it's normal, 10 years. If it's not normal, a physician will tell you, and they will take polyps out during a colonoscopy. And if, obviously, if you have someone, you have family history and genetic history, you should do it sooner and talk to your PCP and gastro to see if you need to be screened sooner than 45.

If you have transgender women after vaginoplasty, this is really important because I don't think lots of people know about this, if trans women had a vaginoplasty, basically had their neovagina constructed surgically, there are times, there are instances when the part of colon can be used as the vaginal canal. So we need to make sure we screen that neovagina as well for colon cancer because the tissue is the same. We want to make sure there are no polyps or anything there.

Genetic counseling, we want to make sure that obviously you have a risk, get that done. Often it's recommended for cancer if you have a cancer diagnosis in a family member, especially immediate family member, personal diagnosis of younger age, and undergoing gender-affirming procedures, especially we're talking about top surgeries. That's definitely, at least at NYU, they prefer genetic counseling. And helps identify prevention strategies, but there's still many, many, many unknowns that we don't know.

And that's all about the screening and genetic counseling. I know there was a lot of information there, but again, you'll get the slides so that's okay. You can always look them up.

But I want to share resources with you. Those are national resources and please feel free to snap a screenshot or take a picture of that because I feel those resources are really important. And obviously, Sharsheret should be number one here, but that I assumed before I put it in the slide. But there is a National

LGBTQ+ Cancer Network. They're really proficient in everything from prevention all the way to survivorship. So if you ever need help of anything, feel free to reach out to them or to me and I'll help you out. Just send them... There's a coordinator that we can just connect them directly to you with them.

And there's obviously other organizations, like SAGE for LGBTQ+ elders, especially in New York City, they're really big, and Cheeky Charity, this is the anal cancer prevention and colorectal cancer prevention organization. And we have FORCE, genetic counseling, many others on this list. Just mentioned those big ones because they pertain to the slides I've just presented.

Don't hesitate to reach out. I put my information. But again, I understand that some of you may not be from New York City and that's totally okay. You can also reach out to me and I can do my best to help you out, but just know help is always available. It may not be within a very close proximity to you, but there's always help in any case.

We usually, on the behalf of the Perlmutter Cancer Center, we do have LGBTQ+ Patient and Family Advisory Council that we ask our patients if they want to be part of that and/or their caregivers and it's open to everyone who got treatment at our institution. That helps us to adjust protocols or create something new. And you have no idea how many numerous advices that I've got from them from our community outreach events and those worked out so beautifully and I'm so thankful to that little group of folks that are just incredible and spend their time with us every two months for a whole hour in the evening when everyone's tired.

Also, there's our website. I put a QR code there. You can just snap a picture of the QR code and check it out. There's also a website, email. That's of our program. Comes to me. Yeah, and thank you so much.

Jenna Fields: Thank you so much, Alex, that was so informative and I really appreciate your expertise in this area. It's vast knowledge and I see that Gabriel is adding some extra resources in the chat, which is wonderful.

A few questions that have come up, and feel free to add questions to the chat during this Q&A. Alex, I'd love you to expand a little bit about why genetic testing is so important before someone is considering a top surgery or a mastectomy in this context.

Alexandr Trifon...: Yes, thank you for the question. And if you're getting a surgery, especially top surgery for trans men, we're talking about chest masculinization, it's not your typical mastectomy. So no surgeon, or you as a patient, no one wants to find out a surprise in the OR when they take out your tissue, especially if they're trying to masculinize your chest, sorry, it's a hard word to pronounce, and they leave some tissue behind. So they want make sure that if that's the case, then they do genetic testing, and when they take out the tissue, they send it for pathology no matter what, even if it was negative.

So yeah, that's why it's really important. And also, it reduces risks for ovarian cancer, for example. So if you genetic testing positive, then they obviously have to make sure that you have to screen yourself for ovarian cancer.

Jenna Fields: Yeah. I really appreciate the conversation around providing a proficient provider. I don't think I've ever heard that particular language before and I found it so valuable. And Gabriel, you spoke about that as well.

I'd love for you to share maybe a little bit, tools that patients can have in their toolbox when thinking about finding a proficient provider, what are some of the things that they should be looking for, thinking about when finding the right match? And Gabriel or Alex, either one of you.

Gabriel Glissme...: I can go. Yeah, I mean, I think there's a lot of things folks can look for. I used to work at the National LGBT Cancer Network, so we would tell people all the time there's some visual identifiers of are there flags places, people have pronoun pins on, when the provider knocks on the door and quickly opens the door, do they say, "Hi, my name's Dr. So-and-so and I use X, Y, Z pronouns. What's your name? What pronouns do you use?" Those types of things.

So yeah, so some indicators like that, or as you're looking on the website for different clinics or hospitals, sometimes you can look at the provider's experience. So sometimes they'll have won awards for things or they will have done a specific fellowship specifically for LGBT folks. So yeah, so there's some indicators like that.

Sometimes I really like Googling, doing a really quick Google search for the whole name of my provider, and that usually brings up a lot of stuff. So if they've done webinars, if they've published papers, anything like that, or like Alex said too, sometimes just reaching out to either folks in your community locally and being like, "Hey, I'm looking for a new provider. Do you have any recommendations?" And they might be like, "Well, I don't have anyone, but I know some people who might," and that's how you can also get some great providers.

Jenna Fields: Wonderful. Alex, I don't know if you have anything to add?

Alexandr Trifon...: I'm just totally piggybacking what Gabriel just says. I think yes, it's really important. So for example, here when I teach staff and faculty for LGBTQ+ knowledge and awareness, I always tell them, I was like, "Listen, I want to..." I have a pin, which I want to show you. We have those pins. So they're like, "Can I have a pin?" I'm like, "Nope. Did you do the training?" They're like, "What do you mean? I want a pin." I was like, "No, visibility is great, but visibility is nothing without support."

So yes, I hope more places think the same way because I feel like that way, if... Let's say someone sees your pin and they're like, "Oh my God. Hey, I'm sorry. Can you refer me to this whatever ABC resource?" And I'm like, "I have no idea what you're talking about." Or on the other hand, it's like, "Oh, listen, actually, you know what? I don't know, but I know the person I can connect you to." This makes such a difference, right?

Or if you know, great. And yeah, I mean, just do research. Also, look up if they have done any webinars or talks, abstracts or anything at LGBTQ+ conferences or are they members of those organizations? Also, there is an amazing website now, it's national, called LGBTQ+ Provider Directory. I can put a link in the chat shortly while we're talking. You can just, by state, you can just put specialty that you need or whatever services that you need and it can have some lists. Again, it's not all-inclusive because the providers put themselves on the list, but it was created by GLMA and their committee. It's Gay and Lesbian Medical Association, which is also expanded to all identities now. Yeah, that is a great website. I'm going to Google the website now to put it in the chat for everyone.

Jenna Fields: Thank you. And I know Symone put in one as well a little while ago when you were talking about this. I don't know if it's the same one or a different one.

Alexandr Trifon...: I didn't see, but-

Jenna Fields: Good to have multiple resources.

Alexandr Trifon...: Sure.

Jenna Fields: Sandra, I'd love to ask you, you spoke so beautifully about the role that your wife played as a caregiver and your experience and some of the challenges that you also faced. I'd love to hear or maybe you can share some insights on how a caregiver, the story you shared about her calling health insurance company was such a good one, but any other tips for caregivers who are watching this webinar that they can think about when providing support to their partner going through cancer treatment?

Sandra Chefitz: Yeah, I think that so much of this depends on the person, but I think that I would recommend that caregivers, significant others, partners, friends, read as much as they can to understand what your loved one is going through rather than waiting for your loved one to explain it. And it's hard to talk about and you're tired already.

I did a lot of research. I'm that kind of person. I value that in other people. But I think that the best way that you're going to be able to help be there for someone else or take care of someone else is to understand a little bit more about what they might be going through. Keeping in mind that the experience is really different for everyone, but what are the common things they're going to encounter and how can you get on top of that for your loved ones so that they don't have to figure it out on their own and also walk you through it or explain it to you? So, research.

Jenna Fields: That's great. And Gabriel, I'd love to ask you, I think you were so generous in sharing with us your own times that you've delayed screening and admitting to that. I think everyone can relate to that. It's very easy just in general to put off your screenings and obviously when you face additional barriers as well. I'd love for you to share maybe what are some affirmations or tips that you can give people when they're going through the mental challenge of making that phone call? What helps to get to pick up the phone?

Gabriel Glissme...: Yeah. I think as I was going through it, I was like, "Does anyone like pap smears?" I feel like they are... I don't think there's anyone on the planet who likes them. But yeah, I mean, it was kind of tough because obviously I was forced to get a pap smear via my insurance to get surgery and everything. But yeah, just I think the drugs helped for sure that I was prescribed by my OB-GYN.

But yeah, just remembering just like, "This is temporary. This is pretty fast." Pap smears feel like they're a very long time, but it is seconds essentially. So yeah, "This too shall pass. This is going to be very quick. It feels really long, but really these are seconds. You're going to be okay. You've been through more difficult things. This is a barrier that you have to get through to get the rest of your care done and so you can survive this because you're going to have to survive surgery in a couple of weeks."

And so yeah, I think it was just a lot of mindfulness, and I think in Jewish tradition, you have Musar and a lot of that is mindfulness and really just calling on those traditions as well of just trying to obviously be present in my body while also trying to forget where I was, but just thinking about how amazing it is that we even have testing and screening like pap smears and that we can catch these things, and just being present in the marvel sometimes that is cancer prevention screenings.

Jenna Fields: Yeah. Yeah, definitely. I'm seeing some chatter in the chat. I just want to make sure, my colleague at Sharsheret mentioned that we do have a meditation series that we developed and also caregiver support. I saw what was written about taking care of yourself while you take care of your loved one. So just please know for anyone on the call that we do offer caregiver support as well.

Okay. Last question before we wrap up. Alex, you shared just a phenomenal amount of information around screening for the LGBTQ+ community and considerations that folks should be thinking about depending on what organs need to be screened. Where can people stay on top of screening recommendations, particularly for the LGBTQ+ community?

Alexandr Trifon...: Two things. The first thing is find a provider that is proficient in care.

Jenna Fields: We're circling back to that.

Alexandr Trifon...: Yes. And I know you love the word now.

Jenna Fields: Yeah.

Alexandr Trifon...: So meet your LGBTQ+ proficient provider who educated themselves based on research, based on the articles, based on experience of other clinicians across the country and across the world, and the guidelines at WPATH might possibly put it. WPATH is organization to put together the standards of care for transgender folks. It's a worldwide organization.

Jenna Fields: Say the name again. I'm sorry, I didn't catch it.

Alexandr Trifon...: WPATH, WPATH.

Alexandr Trifon...: Yeah. And to do your own self-education, right? Just read the papers, read the experiences, and also just read up on papers. I think the clinicians who've done their research, and if you don't have such clinician, unfortunately, educate yourself, ask peers and folks that have similar experiences or similar kind of situation. They've been in same situations or whatever. But yeah, I think those two things very important.

Jenna Fields: Wonderful. Well, thank you so much to the three of you for this really excellent conversation. I really appreciate your time and your expertise and your personal experiences. And I feel like I should mention that Sharsheret does have a Know the Facts booklet that's specifically for the LGBTQ+ community, and it includes information both on hereditary cancer risk in the Jewish community, as well as screening for the LGBTQ+ population. I'll ask my colleague to put it into the chat. It can be downloaded or you can request a hard copy and we can send it to you.

As I wrap up this webinar, I want to thank our generous sponsors, the Basser Center for BRCA, Cedars-Sinai, Genentech, Novartis, and Cooperative Agreement 24-0061 of Centers for Disease Control and Prevention, as well as a huge thank you to our program partners who supported and promoted the webinar. Please take a moment to fill out our evaluation survey. My colleagues are going to link it in the chat box right now.

Jenna Fields: Please remember that Sharsheret is here and we provide emotional support, mental health counseling, financial assistance, and community health education designed to help you navigate your cancer experience and all of our services are completely free. And we're going to put that information in the chat box as well.

One more time, a huge thank you to our speakers this evening, and please fill out the evaluation and we look forward to seeing everybody soon. Thank you again and have a great evening.