

Unique Issues of Lesbian and Bisexual Cancer Survivors Teleconference

Tuesday, March 20, 2007

LORETTA: Good evening. My name is Loretta, and I will be your conference operator today. At this time I would like to welcome everyone to the "Unique Issues of Lesbian and Bisexual Cancer Survivors" conference call. Ms. Carter, you may begin your conference.

KHADIJAH CARTER (MODERATOR): Thank you. Good evening, and welcome to the teleconference, "Unique Issues of Young Lesbian and Bisexual Cancer Survivors," hosted by the Young Survival Coalition and the Mautner Project. I am Khadijah Carter, a four-year breast cancer survivor and the diversity and programs manager for the Young Survival Coalition. The Young Survival Coalition is the only international network of breast cancer survivors and supporters dedicated to the critical concerns and issues unique to young women and breast cancer. The diversity outreach program aims to support a committed, connected and diverse community for young women regardless of race, ethnicity or sexual orientation to ensure that all young women affected by breast cancer have access to the information and support they need. I would like to introduce my co-moderator, D. Magrini, the health education coordinator for the Mautner Project.

D. MAGRINI (MODERATOR): Good evening, everybody. This is D. Magrini from the Mautner Project. And I'd like to tell you just a bit. The Mautner Project, I believe, is 16 years old now. And we are dedicated to social justice and the health and welfare of lesbian and bisexual women. We're having this conference for healthcare professionals and advocate survivors to address the various issues faced by young lesbian and bisexual women throughout their cancer experience. We have five panelists who have so graciously taken time to be here with all of us tonight. And then let me introduce our first panelist. Khadijah, did you want to

say something in here?

KHADIJAH CARTER (MODERATOR): Before we hear from our panelists, I would like to provide you with the logistics of tonight's call. Tonight's call is being recorded, and a transcription will be made available on the YSC's web site, www.youngsurvival.org, and the Mautner Project's web site, www.mautnerproject.org, in the coming weeks. The format of the call is as follows. Each presenter will impart her knowledge and experiences to you as a healthcare professional or advocate survivor. The segments will be in this order: coming out to healthcare professionals, fertility and body image. Questions will be taken mid-way after each segment. If we run out of time and you still have questions for the panel or wish to receive full bios for the healthcare professionals, you can submit them to diversity@youngsurvival.org. We will do our best to get an answer to you. I will now turn this over to D. Magrini.

D. MAGRINI (MODERATOR): Very good. I'd like to introduce Christine Benjamin. Christine Benjamin is a seven-year cancer survivor. She and her partner, Karen, were together a year before the diagnosis. Christine is a licensed, non-practicing psychotherapist and a photographer currently working on a book of portraits on breast cancer survivors. She works closely with the Young Survival Coalition in their diversity efforts, the POC(?) program and is a member of the board.

Dr. Margaret Lewin is a board-certified internist with a subspecialty with board certification in hematology and oncology. Her private practice in New York City is centered on primary care. She has a special interest in travel medicine, and has traveled extensively, working across many different types of cultural barriers. Affiliated with the New York Presbyterian Hospital at Cornell, she has been widely published and is a frequent lecturer. She volunteers at Callen-Lorde, a community health center that provides quality healthcare and related services to

New York's LGBT communities regardless of their ability to pay and promotes health and education and advocates for their health issues. Please, ladies.

CHRISTINE BENJAMIN: This is Christine. Thank you for that introduction. I wanted to thank everyone for attending the conference and for helping to raise the presence of lesbian/bisexual women in the YSC. I think it's been quite a presence this year. And for that I am very grateful and very happy. When I was thinking about what to talk about tonight, I started thinking about how I handled out coming out to healthcare providers before cancer and then after cancer. So I noted that there was quite a difference of before cancer.

When I would go and see a new doctor, inevitably they would ask the question, "What do you use for birth control?" And I lived in Denver at the time, being from New York City, being a bit of a smart aleck, I would answer, "A woman." And that was sort of my way to be humorous about it but to also shock them, in a sense, to encourage them not to be so heterosexist and to perhaps think about opening up the boundaries a little bit. And the way that I would handle it was just by on the medical and registration form I would often enter my own options. I would say that I have a partner or that I have a domestic partner. I would just add something else. And that would give them the information that I am a woman who is partnered with a woman and that would be an indication that I have some different healthcare needs.

However, at the time of diagnosis I was pretty overwhelmed with being diagnosed with breast cancer and didn't really think about that. And fortunately I went to see Dr. Lewin in Manhattan, in New York City. And we sat down and talked. And she asking my history, and one of the first questions she asked was, "Do you have sex with men, women or both?" I was sort of taken aback by the question, because no one had been so forthright with me. But I was delighted and relieved that my concern about coming out was taken away with that one question

that provided so much information.

But I also marveled at the simplicity of the question and how it freed me to not have to identify or classify myself. Dr. Lewin then informed the woman who became my breast surgeon of my sexual orientation and that my partner, Karen, would be accompanying me to the appointment. I still think to this day that Dr. Lewin and I don't really agree on this. She doesn't believe that she came out for me to the other doctor. But I'm sure it was the case. And it just relieved this whole tension of having to do that, so I felt very, very fortunate.

However, I went to another doctor, two other doctors, for second and third opinions. And when I introduced myself they took my hand and greeted me. And then I introduced my partner, Karen, and both doctors glanced at her and then just ignored her, didn't shake her hand, didn't ask her to sit down. They completely ignored her. And we were startled at that. We couldn't believe that it was sort of blatant discrimination. It made us feel very, very comfortable. And in the end I have to say that it weighed in in my decision-making process in choosing a doctor.

Later on, after surgery, Karen was waiting with my family and some friends in the waiting room. And when my parents were able to come in to the recovery Karen wasn't allowed. Even though we had the appropriate paperwork filled out, she was still not allowed in. And fortunately the breast surgeon happened to walk by and overrule the nurses and she was able to come in.

So my experience has been completely incredible with Dr. Lewin and how she was able to, with that one question, just relieve all of my fears and all of my concerns about having to come out and essentially deal with that issue on top of a breast cancer diagnosis. And then conversely, dealing with what felt like blatant discrimination and at least just an

uncomfortableness on the doctor's part to treat us as equal, to treat Karen as an equal participant in my treatment. So I think that's all I have to say.

DR. MARGARET LEWIN: Hello, this is Dr. Lewin. I have to tell you how much I enjoyed working with Chris and with Karen. They were such a strong, intact couple that for those of us open enough to recognize the strength of their relationship it was really inspiring. But I'm a strong believer in primary care, in which you have a central doctor who helps you coordinate all of your healthcare, including the oncologists and the orthopedists and the radiation therapists. And you're right, Chris, I probably did say something to the surgeon.

But having a primary care doctor is sort of like having a life partner rather than a one-night stand. To get the most out of the relationship there has to be a comfortable give and take, which includes being comfortable discussing your sexuality, because it's at the core of your being. For example, as a doctor, I would be severely handicapped in helping a woman who wouldn't open up about her sexuality or about post-traumatic stress or the fact that she was raised in Rwanda and went through that kind of a childhood. How else can you open up enough to some day say something like, "Doc, I think I have a drinking problem." You really need to be able to be that relaxed with the person that you choose as our doctor.

But there are other important things to address including fertility, having your partner next to you and perhaps making decisions for you in a medical crisis, as Christine alluded to, in other words, drawing up a healthcare proxy. And I contend that when you find the right doctor and she happens to be a heterosexual that you're obliged to teach that doctor, because she will, in turn, train other doctors, so that you eventually have something of a cadre of doctors who can offer much better healthcare to the whole LGBT community.

LORETTA: Your first question comes from Renee from Bethlehem,

Pennsylvania.

RENEE: Hello, thank you for having this conference call tonight. I'm a lesbian, and I'm a ten-year survivor. I'm in my tenth year as of this month. The doctor mentioned something about the healthcare proxy. Could you expand on that a little bit?

DR. MARGARET LEWIN: A healthcare proxy in New York State enables someone to designate two people who know what the wishes of that woman would be in case she couldn't make her own decisions. Then those healthcare decisions are delegated to person number one, and if person number one is not able to participate, person number two. And that carries the weight of the law. This is a state-determined issue.

RENEE: All right, thank you.

LORETTA: There are no further questions at this time.

D. MAGRINI (MODERATOR): Shall we move on to the next segment? Yes?

KHADIJAH CARTER (MODERATOR): Yes.

D. MAGRINI (MODERATOR): Our next segment will feature fertility. One of our presenters will be Dr. Emily Blake, and I will read her bio for you. Emily Blake, MD, is an obstetrician/gynecologist with a subspecialty training in reproductive endocrinology and infertility. Her post-graduate studies also include genetics and early embryonic development. After many years in clinical practice in infertility, she researches fertility treatment. She lectures on fertility options for lesbians and the gay community.

KHADIJAH CARTER (MODERATOR): Hi, I'll introduce Liz Cooper. Liz Cooper was diagnosed with invasive breast cancer in November 2000 and had a lumpectomy in December 2000 and radiation thereafter. She went through two IVF procedures that resulted in the retrieval of three eggs that were fertilized at the time. She has decided against getting

pregnant herself, and she is still considering whether to pursue surrogacy. Liz is a law professor teaching in New York City. Liz, we can open up with you, thank you.

LIZ COOPER, ESQ.: Thanks so much. I was 39 years old when I was diagnosed. I actually was in the process of trying to get pregnant. The fact that my cycle was coming up and that I was going to go in for my third attempt probably, in fact, definitely facilitated my getting care sooner, because when I went into the doctor that morning I said, "Can you check out this lump before you thaw out the sperm?" I had felt something the previous Friday. This was Tuesday morning, election day, the start of Bush v. Gore. And my partner had said, "Oh, I'm sure it's nothing. No big deal." And I almost didn't say anything to the doctor. And of course in retrospect I'm immensely glad that I did.

She sent me off to get a whole series of tests that day, and within 24 to 72 hours, I knew for sure. I knew that Friday for sure that it was breast cancer and I was going to have to do something. I went to see four different surgeons before I found someone who I was very comfortable with. But ironically enough, she was not the one that raised the fertility issues. Of the four that I saw, only one raised fertility concerns. I went to each of these appointments with my mother, my father and my partner. And that one doctor referred me to Dr. Kutluk Oktay, who does a great deal of the fertility work in New York. And so I went to see him.

Ultimately I decided that I would go through IVF cycles where my eggs were retrieved. Normally for women who are going through IVF you get very high doses of hormones. And even if my tumor had been estrogen negative ... they didn't know that at the time. Regardless of the hormone status of my tumor, I don't know that they would have consented to giving me, or that my oncologist rather would have given me permission to use hormones. But I didn't feel comfortable using hormones anyway. And I enrolled in a trial where

they were using tamoxifen to stimulate egg production.

Out of the two IVF cycles, both of which were done before I started chemotherapy, they were able to retrieve a total of three eggs. Now, in some very ironic way I was lucky, because I had sperm on hand because I was trying to get pregnant. This is a concern that heterosexual women with fertile husbands don't have to worry about. But for lesbians who want to try to retrieve eggs, I know that the technology is getting better about freezing eggs. But at least six years ago it was not viable at all to go that route. And even now I think it's not fully reliable.

So I went through the two retrieval processes, which were incredibly expensive and major hassles, but felt tremendous relief at the time. I think that I was really less focused on my mortality and more focused on my fertility, since I had been in the process of trying to get pregnant. What no one told me about at the time was the potential risks of getting pregnant afterwards or the incredible expense of hiring a surrogate. Each frozen embryo, it's not even quite developed to be an embryo.

But each frozen embryo that I have, there's about a ten to 12 percent chance that it might actually turn into a fetus that's carried to term. So if I were to be able to hire a surrogate, I would have about a 30 to 35 percent chance of it working. So these are things that I wish that someone had shared with me in advance. I don't know that I would have made a different decision, but it would have been very helpful to come to terms with it. As it is right now I have not done anything with these fertilized eggs, in part because of the prohibitive cost of surrogacy. And I'll leave it at that, and if there are questions I'm happy to try to respond to them.

LORETTA: You do have a question from Mindy from New York, New York.

MINDY: I was just wondering if you're still with your partner whether she would

consider carrying the embryo or trying to, if that's a possibility.

LIZ COOPER, ESQ.: That's a really great question. My partner and I have since broken up, actually in part related to these fertility questions and childbearing questions. She was not interested in becoming a parent and is nine years old than I am. So she had no interest and a lessened ability to get pregnant. It also depends upon the state that you live in. In New York technically surrogacy is illegal. And most facilities that I know of will allow you to use a family member as a surrogate.

Now, as a lawyer, it's an interesting question. As a lawyer and as a cancer survivor, it's an interesting question whether you could make the argument that your partner is, in fact, a family member and, therefore, should be able to carry or try to carry the embryos. It's actually a very interesting question. The other possibility would be to go to a state where surrogacy is legal. You could go to New Jersey, Massachusetts, California, any number of other states. But you'd have to consult with lawyers. I don't want to be pretending to give legal advice here. And probably do the implantation that way.

LORETTA: There are no further questions at this time.

D. MAGRINI (MODERATOR): Has Dr. Blake had a chance to add to the conversation?

EMILY J. BLAKE, MD: Interestingly, I have almost an opposite reaction in a certain way to Liz's comments about the difference for being a lesbian or being a heterosexual and having to deal with the potential outcome of cancer treatment. Especially because this is for young survivors, so we're talking about younger women who may or may not be in a long-term relationship, there's a way in which being lesbian opens us up to a couple of extra options that aren't available to heterosexual women who will subsequently then marry a man who may have

more issues about the sperm donor for the embryo. So I'll start off with technology, because that's really what we're talking about.

I'm not really going to speak about the effect on fertility of the various cancer treatments, because my background is not as an oncologist. My background is as a fertility specialist. But there are different treatments, and some carry a higher risk of permanent infertility and some don't carry as high a risk. So that's going to depend on both the cancer and the treatment option that you're offered. But with a lot of chemotherapeutic agents, it's fairly common that one of the sequelae of treatment may be that, in fact, you go into an early menopause.

So one of the options is what was discussed with Liz, which is to do an egg retrieval and then fertilize the eggs. As she spoke, she said that there are really not good methods right now for taking eggs and freezing an egg and having them be viable and usable later. There's some of that done experimentally, but it's purely experimental, and the success rates are very low. Similarly, there are some people that will actually remove the entire ovary and cut it into thin strips and then freeze that. And that also is purely an experimental treatment form or option. And the results from that are also fairly low, so the highest chance of really maintaining pregnancy options is to freeze embryos.

Now, in order to do that, you need to have some source of sperm, which for a lot of lesbians, might be from a donor sperm bank. And that's sort of where I think lesbians have a little bit of an emotional advantage over heterosexuals who are intending later in life to find some guy and marry him, because if later in life we're settled with a woman and we have embryos conceived with some donor sperm, it's obviously less of an emotional issue, because there was going to be some donor sperm used at some point or whether there's a known donor, a

friend or anonymous, but at least it's not as if your woman partner could donate the sperm herself. So in a sense that makes it a hair easier.

We also have a couple of other advantages, which I think Liz also kind of alluded to, which is first of all if you have a partner ... if your intention is to have children, you may or may not be as committed to providing the genetic material for those children. So as a lesbian if you go through a premature menopause but your partner is of your age and not going through premature menopause, obviously, then you can still have children in your life. You can still (Inaudible) parent. So that's another option.

Then the other option is if you do freeze embryos you can use them if your diagnosis doesn't really make it safe for you to go through a pregnancy. And depending on the kind of cancer you have, if it's hormonally sensitive you may really be advised against conceiving a pregnancy. Your partner could, of course, potentially carry the pregnancy to term instead.

Now, none of that speaks to the issues Liz was talking about, which are the expense of all of these procedures. These are expensive. The medications, the retrieval is done in an operating room. Embryos are obtained and frozen. All of that comes with a big cost. If you end up choosing to use a gestational carrier, a surrogate, somebody that you specifically hired to carry the embryos to term, that's hugely expensive. So there are a lot of down sides to it.

But technologically we have some varied potential options. And depending on your age and depending on the type of cancer that you have, you could actually do a regular in vitro fertilization stimulation protocol and end up with a significant number of eggs, which could be fertilized and stored as embryos for use at a later time. So we do have a variety of options. None obviously are all that great, but we do have some things that we can think about.

There is at least one other experimental concept that's being talked about, and I don't know how much this has been used. And I don't know how successful it is. But depending, again, on the type of cancer, there is a thought that it's possible to either chemically put your ovaries into a state of quiescence in the hopes that they're less sensitive to the chemotherapeutic agents. We use a gonadotropin-releasing hormone agonist, which is actually what we use to do a regular in vitro fertilization cycle as well. And that may or may not, as we learn more about it, provide a way to sort of protect our ovaries from some chemotherapeutic agents.

And some people who are concerned about radiation therapy, especially if it's of the pelvic organs, you can actually move the ovaries up and out of the way so that they're not hit by the radiation and therefore you're able to retain your fertility for longer. One thing is that I think it's true that a lot of physicians don't think to bring this up, and I think it's true that there's a lot of surgeons and oncologists who are more focused on the cancer and the treatment for the cancer than on the rest of your life. And I think we need to do more education so that people speak to these issues better and more frequently to bring them up to somebody who's in the midst of their own trauma with having had a diagnosis. But also it's important for us to educate each other so that we can bring that to the doctors that we speak with. I think I'll take questions beyond that.

LORETTA: You have a question from Laura from Ypsilanti, Michigan.

LAURA: Hi, this is Laura from Ypsilanti. I wondered if you could talk a little bit about the process of after you harvest the eggs and have these embryos, what's the process of ... we haven't really talked about what the next step is of carrying it for the partner. And is there kind of an age limit of when it's healthy.

EMILY J. BLAKE, MD: Sure. I'll see if I can answer what you're hoping to get out of this question. You're talking about really not the immediate steps after you freeze the embryo, but in the long run to take that frozen embryo and make it into a baby. Is that what you're asking?

LAURA: Exactly. What steps are involved and what kind of the age range is in terms of the health for myself of the carrier or the partner?

EMILY J. BLAKE, MD: The age that's most important is the age of the woman at the time that the egg is retrieved. I don't know if you've seen in the news, there are lots of movie stars now that are significantly older who are having babies. They're not doing it with their own eggs. There was a woman who was 63. I think that's the oldest one that they've owned up to, at least, who carried a pregnancy to term. Again, not with her own eggs. So the limiting factor is not really the age of the carrier but is the age of the donor, the age of the woman at the time that the egg is retrieved.

And that's important for a couple of reasons. One is because the perkiness of the ovaries is going to determine how many eggs you'll be able to retrieve in response to whatever stimulation you're doing, so how many embryos you're going to have. And also whether those embryos are at a more or a less risk for having a genetic abnormality, which will make the embryos less viable. So we don't really have an age cut-off. The age cut-off is more related to what it means for an older woman to have a newborn and how long you're going to live to raise the child.

So in general we use 40s to 50s as a cut-off for somebody to carry a pregnancy. But if somebody is in good health, we can make you be pregnant. There are hormones that we can give you to carry the pregnancy. So don't even have to be menstruating. You don't have to

have a normal menstrual cycle. Exogenously we can give you all of the hormones you need to prepare your uterus to accept an embryo and to carry it to term. Obviously if you have medical problems, if you're older and you're getting hypertension, then you have other risks that would be significant or important to the pregnancy itself for you being a pregnant woman. So that sort of becomes the next issue of how to deal with that.

LIZ COOPER, ESQ.: This is Liz. If I can just add one thing to what Dr. Blake was talking about. The place that I went, let's put it this way, they're not used to dealing with lesbians. But what they did say to me is that the oldest I could be for them to implant the embryos in me, at least, was 50 and a half. I think that's what it was. And beyond that they would not implant them in me. So even though it's technically possible, you probably would want to check with the facility that you're working with to make sure that age would not be an issue.

EMILY J. BLAKE, MD: And you'd really need to discuss it with someone, because as I said, there have been a couple of women who are in their mid-60s. Most of them have lied to the physician about what their age was when they said they wanted to do donor egg. I mean, these are women that say that they want to be mothers themselves. Most offices and clinics do have age cut-offs that they follow. But there may be some discretion within that, depending on your circumstances. So it's important to talk about it.

LORETTA: There are no further questions at this time.

EMILY J. BLAKE, MD: Did that answer your question, Laura?

D. MAGRINI (MODERATOR): Are there other questions?

LORETTA: Your next question comes from Laurie of Ypsilanti, Michigan.

LAURIE: Hi, I have a follow-up question. My partner asked the question before,

the question that I'm going to ask, and that was about the legal issues around my partner carrying an embryo fertilized with my egg and a donor sperm. How do we go about figuring out what all of the legal issues around that are? We live in Michigan, and Michigan just passed a law banning gay marriage and also has taken away domestic partner benefits for LGBT people who work in public institutions. So we're kind of in a hostile state now. I just wanted sort of to get clear about legal issues. Where would I go and what type of lawyer would I look for and what kind of questions should I ask? Thank you.

LIZ COOPER, ESQ.: This is Liz. I can take a crack at trying to answer your question. You definitely would need a family law attorney in Michigan, because as you were indicating even in your question, all of the relevant laws are very state-determined and locally determined. If you don't happen to know a family law attorney who would be both incredibly talented and LGBT friendly, my guess is you could probably contact the people at Lambda Legal Defense. And they have a Midwest office in Chicago as well as their national office in New York. There's also the National Center for Lesbian Rights out in San Francisco. So the other thing would be to probably network and talk with your friends to see if they have someone who they really trust who maybe did a will or a healthcare proxy or something like that, basically to network your way to a really talented lawyer.

EMILY J. BLAKE, MD: I just want to add one thing, which is there is more than one way to look at this when you're trying to negotiate it through. And the first thing is you really need to figure out all of the legal status so that you can be protected. But in terms of the embryo itself, there are two different ways you can look at it. You can look at it as a surrogacy pregnancy, meaning that the woman whose egg it was is the mother and she's looking to her partner to gestate this pregnancy for her, which would make it surrogacy.

The other way you can look at it is as a donor egg cycle, which is that the partner who did not provide the egg or the embryo is looking to adopt the embryo. And I just think it's important to realize that you could look at it in either of those ways, because as Liz said, there are many states that don't allow surrogacy. But those same states will allow donor egg cycles, and so you could use a known donor for your egg. Again, none of this at all takes away the whole issue that you really need to get everything in place beforehand legally so that your child isn't left in a limbo and so the two of you really know where you stand with it.

LORETTA: There are no further questions at this time.

D. MAGRINI (MODERATOR): All right, then, we'll move into our next segment. The next segment will feature body image with Michele Forsten and Liz Margolies. And their bios are as follow. Michele Forsten is co-founder of the New York City Lesbian Cancer Support Consortium and the co-facilitator of a cancer survivors group in New York City's LGBT Community Center and SHARE. In 2004 she won the Sarah Pettit Memorial Award for Excellence in Journalism sponsored by the National Association of Lesbian and Gay Journalists for a series on breast cancer. Her columns have appeared in *The New York Times*, *MAMM Magazine* and GLBT newspapers around the country. She grew up on Coney Island and is a college administrator and published and produced playwright. I'll give you her web site here. It's www.micheleforsten.com.

And Liz Margolies, LCSW, was the original coordinator of the Lesbian Cancer Initiative, the first program in New York City devoted exclusively to the needs of lesbians, bisexual women and transgender men and women with cancer. She is also a psychotherapist in private practice specializing in trauma, loss, health disparities and sexuality. In addition, Liz coordinates the mediation group at the LGBT community center, directs a bereavement program

at three animal hospitals and teaches social justice at Fordham University Graduate School of Social Service. She was very active in the long-term recovery efforts in lower Manhattan following the attacks of 9-11. Liz has published several scholarly articles, a training manual and lectures around the world. Liz is currently developing the first national program for GLBT people with cancer.

LIZ MARGOLIES, LCSW: Hi, this is Liz Margolies. I am going to be speaking with Michele during this segment, and we have spoken together before and actually prefer to have something that resembles a dialogue. So I will give a little introduction, a little background. And then Michele will speak about her personal experience and some of what she's learned from leading the support groups, and then we will continue talking together. And then afterwards we can take questions. And I also want to say thank you, everybody, for calling in.

I was thinking about this talk today and the first question I wondered was how are young lesbian and bisexual women different from other young survivors in terms of body image. In some ways I decided we are not that different. Lesbians are women first and foremost, and we have a whole range of feelings about our bodies. Even before the cancer diagnosis or surgery, chemo, radiation, some people love their breasts and derived a great deal of sexual satisfaction from having them touched while others always had some complaints about the size or shape or sensations in their breasts. We didn't all start out the same.

And as with all breast cancer survivors, whether young, old, gay or straight, it's not easy to adjust to a new body after treatment. After cancer, the body is forever altered. And for younger women, this may be the first set of scars or the first surgery of their lives, meaning it's even harder to adjust to. And the scars or the physical changes are forever reminders of the cancer, which is perceived by some people as the first betrayal of their body. The scars may also

be reminders of the fears that they have or had about their future or about the cancer's recurrences. With scars, I'm suggesting there's no forgetting cancer.

All breast cancer survivors have to come to terms with the new body and learn to accept it, and Michele will talk a lot more about this. But in some ways I think young lesbian and bisexual breast cancer survivors are likely to have some different feelings or pressures and experiences than our heterosexual sisters. As one example, lesbians are supposed to be not as trapped by male standards of beauty, in this case, the standard that demands two symmetrical and perky breasts. This would suggest that we would have an easier time adjusting to a new body after cancer.

But in other ways acceptance can also be more difficult for some bisexual or lesbian survivors because we face another woman's body in bed. There might have been some pleasure in the mirroring of the two breasts between the two partners, and now there is the reminder of the change as the survivor looks at her partner. Women who have sex with men do not have that reminder when they're both naked.

And while some young lesbian and bisexual survivors actually feel social pressure to embrace their scars or mastectomy like Audre Lorde did or Marilyn Hacker or to tattoo something bold across the flat chest like Deena Metzger's photographed called "The Warrior." I don't know, some of you might remember that. They might feel like they should be comfortable exposing their bald heads, always being the brave warrior or Amazon. But I think the warrior stance is not easy, and it's not natural for many people. When the breast cancer is not hidden or quiet, like with an exposed bald head or obvious mastectomy, the supportive remarks of others don't always feel good. They can feel like pity and exacerbate the isolation or difference from your peers.

I think that young survivors can have an especially difficult time, a unique kind of loneliness in this way. Since age is the greatest risk factor for cancer, the young survivor is often the first person in her social circle to have cancer. And with time and experience, people learn how to respond better. But younger friends and lovers may be more afraid of cancer, might not know that a diagnosis of breast cancer is not a death sentence. And they might not know how to respond well. Older survivors' peers have often had some experience with cancer and tend to respond better.

But I think, and my experience shows, that most young lesbians and bisexual cancer survivors fall somewhere in between these alternatives, alternating between difficulty over their new body, seeing its imperfections reflected back in the mirroring with sexual partners, and a kind of gratitude for survival, an acceptance of the changes and seeing the scars as battle scars of victory. And now, Michele, maybe you can go from my general to your specific and talk about your own experience.

MICHELE FORSTEN: I had my first breast surgery at the age of 16 for a benign tumor. Actually that I had many other surgeries to remove lumps in my breast, all benign until one day it wasn't. Trees have rings that reveal their age. I had visible marks that told the story of the six surgeries I had. Scars were etched around both my nipples, and faded incisions lined the surface of other parts of my breast. As a very young woman, I was very self-conscious about my scars, and I didn't date as much as I would have. And I didn't go topless at Herring Cove on Cape Cod or other beaches.

In my mid-30s I finally accepted that even though I had these scars, my breasts were still attractive. I loosened up some and I went skinny-dipping. I did some nude sunbathing. The scars and the surgeries were no longer on certain stage when I looked at myself in the

mirror. Also, my breasts and nipples still had full sensation, and I had pleasurable experiences to replace the medical ones. That didn't mean it didn't make me sad at times and scared at times. My mother had died of breast cancer at age 46.

Because I had very dense breasts and lots of previous lumps removed, it was recommended that I have a double mastectomy when I was finally diagnosed with cancer in my right breast. It seemed to make sense. I'd had it with being probed and biopsied. The only choice that made sense for me was the one that would require the least amount of follow-up in the future. And I realize a lot of women, they choose lumpectomies, and that's fine. Everybody has to really make their own choice. If I hadn't had a history of prior surgery and biopsies, if my breasts hadn't been loaded with tumors, I never would have chosen such a radical solution.

In the abstract, though, this decision made a lot of sense. I didn't dwell on what a great loss my breasts would be, because I never would have gone through with the surgery if I had. My reconstructed breasts have no lumps in them. It was the first time since I was 16 that this was the case. At the time I was diagnosed I was told there were two types of reconstruction. One was using my own tissue, the TRAM flap, and the other implants. I thought using my own tissue would be the way to go because it was more natural. I was making this decision about reconstruction while still being stunned about the cancer diagnosis.

Not having reconstruction was really not an option for me. The memory of my mother's chest after her radical mastectomy, a disfiguring operation that hopefully is not performed today, was fresh in my mind even though it was a memory from decades ago. My mother had a mastectomy and no reconstruction. She died four years after the surgery. Call it superstition mixed in with wanting to fit in, but I was damned if I was going to go that route. As a kid I had been called string bean, beanpole and other such names. I was always underweight

and drinking Nutrament. Even with my natural size A cups, people often mistook me for a guy with my tall, slender build and short hair. In many ways I am a warrior, but not in this way. I admire those who opt for no reconstruction, but I know it wouldn't have worked for me.

However, if I had to do it again, I would have opted for implants. The surgery I had, the TRAM flap, was brutal. And again it's in my experience. Other people have had the surgery, and I should just say in case some people don't know what it is, the surgery in my case took two abdominal muscles and flipped them up to become breasts. The blood supply still comes from the abdominal area. There is nothing natural about it. Plus like with implants they're not real breasts and don't respond to stimulation like real breasts. Ditto for the nipples, which were crafted from my abdominal scar.

I had been put in touch with a couple of women who had had this surgery before me. And they were very satisfied with the result, which they said included a tummy tuck in the bargain. I didn't really need a tummy tuck, but as a person who likes to play sports, I could really use those abdominal muscles where they belonged. Nobody mentioned, for instance, that the surgery would throw my center of gravity off. I think the women I spoke with were older and sedentary, so the positives outweighed the negatives for them. Those of you who are contemplating reconstruction should keep this in mind. For me it's sort of like if it ain't broke, don't fix it. My abdominal muscles were working fine where they were.

Whatever you do, reconstruction or not, mastectomy or not, you have to get used to what my friend Sarah called the new normal. You had a certain body for some decades, and now you have an altered one. If your breasts were really an important part of your sexuality and you don't have them anymore you have to play up other erogenous zones. Just like if you use one of your senses, your others are heightened. This is either said than done, I've found. I know

I'll always be sad about not having my real breasts, but it's up to me how much I let that interfere with my life.

I used to look better with my clothes off than with them on, and now it's the reverse. Okay, but I can still have an orgasm and enjoy myself. I try to focus more on the positive. I think as you get further and further from your diagnosis and work on accepting the new normal you can redevelop a positive body image if you've lost it.

LORETTA: There are no questions at this time.

LIZ MARGOLIES, LCSW: I wanted to ask you a question, Michele. How much time did you have between your diagnosis and your making the decision about reconstruction? And do you think that if you had more time you would have been able to do more research into the pros and cons of the different options?

MICHELE FORSTEN: I had about three weeks, and that's because I chose to have immediate reconstruction. I just couldn't see waiting and then having another surgery to "look forward to." I am a journalist, and I do extensive research. And every person I talked to who had this surgery was saying how wonderful it was and how happy they were with the response. It just points out that everyone is different. I think if you have a single mastectomy and you have this reconstruction it's easier to recover from it and it might not be as traumatic to your body as having a double mastectomy and having this. And also it depends how much fat you have. I was a thin person to begin with, and I think it was just more difficult for me for that reason also. So I don't know. I think in hindsight I would have done implants, because it wouldn't have affected my abdominal area. But that's me. There are other people who would say something else. But I think if you're very active and you're having a double mastectomy, I still would caution having this surgery.

LIZ MARGOLIES, LCSW: And I know that you've also been leading a survivors' group. What other kinds of experiences have the women in your groups had?

MICHELE FORSTEN: Well, it's funny, one woman came in. And she's a very tall woman. She's a big-boned woman. And she had a double mastectomy and no reconstruction. And her hair is growing back in, and she has this very boyish, attractive look. And she's not thrilled that she had to lose her breasts, but she's very happy with her appearance and she doesn't intend to have reconstruction. Apparently, and she showed us pictures, all 200 of them no less, of when she had her goodbye party for her breasts. And she happened to have double Ds. And in the pictures, in some of them she was holding up the Yellow Pages under one breast and the White Pages under the other breast with no hands holding onto them. So that's how big she was. And she just found that she likes to play basketball and her breasts got in her way. So she's pretty happy with the way she is now. And I think that's as dramatic a different experience from mine as you can get.

LORETTA: There are no questions at this time.

LIZ MARGOLIES, LCSW: I think we can move on.

KHADIJAH CARTER (MODERATOR): Well, now we'll open up the floor for a free forum if people have any general questions that they'd like to ask the healthcare professionals or the advocate survivors, please feel free to do so.

LORETTA: There are no questions at this time.

KHADIJAH CARTER (MODERATOR): This is Khadijah. I'd like to thank everyone so much for their enthusiasm and questions that have contributed to making this teleconference such a huge success. We hope that you've found it helpful and that your questions were answered. Again, if you have more questions feel free to send an e-mail to

diversity@youngsurvival.org, and we'll do our best to answer them. The YSC is here to provide you with the information you need as a young woman with breast cancer and to serve as a point of contact for you. If you are registered on the YSC web site, and I assume that most of you are, you will continue to receive information about upcoming programs, newsletters and announcements that affect you as a young woman. If you are not on our mailing list, please visit www.youngsurvival.org to register. You may also get more information about the Mautner Project at www.mautnerproject.org. That concludes our program for this evening. Again, I'd like to thank my co-moderator, D. Magrini, our presenters, Dr. Margaret Lewin, Christine Benjamin, Dr. Emily Blake, Liz Cooper, Esquire, Liz Margolies and Michele Forsten. I'd like to thank our operator. And the transcript of this call will be available in the coming weeks and it will be posted on the Young Survival Coalition's web site. Finally, thanks to all of you. Stay well and good night.

D. MAGRINI (MODERATOR): Good night everyone, thank you.

(END OF TAPE)