WNPR Radio Voice: Funding for Yale Cancer Answers is provided by Smilow Cancer Hospital. Welcome to Yale Cancer Answers. The director of the Yale Cancer Center, Dr. Eric Winer. Yale Cancer Answers features conversations with oncologists and specialists who are on the forefront of the battle to fight cancer. Here's Dr. Winer.

Dr. Winer (Host): Tonight, we have a special guest, and our special guest, Eileen Williams-Esdaile, is coming to us from Sisters' Journey. Sisters' Journey is a faith-based organization located here in New Haven, Connecticut. And its mission is to ensure that no woman has to face the challenges of breast cancer alone. It was started in 1999 and has provided tremendous support to hundreds of women and their families through the trials and triumphs of breast cancer. Their mission is rooted in advocacy for early detection, proactive treatment, and holistic healing—physically, emotionally, and spiritually. So again, we have Eileen Williams-Esdaile with us tonight. She is on the board of directors for Sisters' Journey and is their survivorship and events coordinator. I've known Eileen for several years, and she's really an inspiring woman who has devoted her life to empowering women and their families who face breast cancer, and in particular, women of color, and even more particularly, women who are Black or African American. Eileen, thank you so much for joining me tonight on Yale Cancer Answers.

Eileen Williams-Esdaile (Guest): Thank you.

Dr. Winer: I'm wondering if you could just tell us a little bit how you got involved in this, which I think means telling us a little bit about when you first had breast cancer and what that experience was like for you.

Eileen Williams-Esdaile: Well, when I was first diagnosed, I was 37, and Sisters' Journey had really just gotten started. But our founder, Linda White Epps—she's a distant cousin of mine as well—and the moment I told her daughter Dawn about my diagnosis, Linda just took me under her wing and never let me go. And after Linda passed with the same thing, when her mother took over. And I've just been involved ever since. And I actually—my children were five and seven at the time when I was diagnosed. And I had no family history. I felt the lump myself and just went on from there, called my OB-GYN. I wound up going to Temple Radiology, and they actually told me that I had nothing to worry about, that there was nothing there. But fortunately, my OB-GYN had sent me for my baseline mammogram at 35. And I guess the day that I went to the OB-GYN, I think every woman in New Haven must have gone into labor. So they were really backed up. So the doctor said, "Well, after sitting there for, I don't know, a good hour and a half," they said, "Would you mind seeing one of the midwives?" I said, "I'll see you at this point, I don't care. I just want to be seen." So when I went in, the midwife, she just started doing a breast exam, and she actually went directly to the lump. I didn't have to tell her the area or anything; she just went right to it. And the doctor, who had actually delivered my daughter, he became free. So he came in, and, you know, the two of them started talking about, "It's a solid mass that needs to be aspirated." And they're

talking above my pay grade. I didn't know what they meant by that.

Dr. Winer: : Well, and at this point, you didn't have a lot of experience with breast cancer either?

Eileen Williams-Esdaile: None.

Dr. Winer: You might be a little more familiar with the language today.

Eileen Williams-Esdaile: Oh, absolutely. Yes. No, absolutely. But long story short, I went to Temple, like I said, they didn't—they told me everything was fine. But then I think by the time I got back to my office, I had calls from my OB-GYN asking me to come back because I guess at some point they looked at my baseline films, and then I guess they saw the different changes or what have you. But again, long story short, it was holiday time because I felt the lump Thanksgiving. So we were running into doctors and providers, taking vacation time and everything else. They ran on. Christmas came, and I really wasn't officially diagnosed until January 14th.

Dr. Winer: Wow. Well, you know, I think that this raises an important issue, which is that particularly in young women, that mammograms oftentimes don't show changes even when there's a lump there. And it sounds like there was some—what was probably—subtle change from the baseline to when you had this lump there, and that helped clue them in. But of course, any time a woman has a lump, whether or not there's something on imaging or not, it absolutely has to be evaluated. And that's even more true in someone who's young. So you ultimately were diagnosed with breast cancer, and presumably you then spent some number of months or much of the next year getting treatment?

Eileen Williams-Esdaile: Yes, I had a lumpectomy. I had chemotherapy and radiation.

Dr. Winer: And at the time, how scary was this?

Eileen Williams-Esdaile: It was very scary. Like I said, my children were five and seven, and that's all I could focus on—was being here for them. And I remember my former mother-in-law was a nurse at Yale. And they mentioned to me about participating in the clinical trial. And again, all this was foreign to me. And I remember I said, "Well, let me run this by her. She's the nurse. She would know better than I." And she said, "No, absolutely not." To this day, I don't know why she told me no, but I didn't do it because I was listening to her.

Dr. Winer: And this is now roughly 2002?

Eileen Williams-Esdaile: 2002? When is this? This is the '99.

Dr. Winer: '99. Okay. And, of course, you know, we have made—to a large extent because of clinical trials—tremendous progress in breast cancer treatment since that time. And women are doing better and better than ever before. Not that the problem by any means is completely solved. So maybe we can shift a

little bit and talk about Sisters' Journey. Dr. Winer: So I'm sure that there are some listeners who have heard of Sisters' Journey. I bet there are not too many who are terribly familiar with the history of the organization and how many members there are and what it's about.

Eileen Williams-Esdaile: Well, like you said, we were formed in 1999 by Linda White Epps right here in New Haven, and she created it after her own diagnosis to connect women of color who were surviving and thriving after breast cancer. And we started out as a small support circle in her living room. We've had a couple of meetings in my living room, but we have grown into a statewide nonprofit that educates, empowers, uplifts women across Connecticut. And as far as membership, if you want to base that on women in the calendar, I mean, it's over 500. When we have our support group meetings, it all depends. Sometimes we'll have 30 at a time. Sometimes we may just have ten. A lot of times we have guest speakers. Sometimes we just sit in, chat and chew, if you will, and let everybody know that this is a safe space. No question is a dumb question. So whatever you're feeling, this is the place and the space to ask your questions and to try to, you know, bounce things off of others.

Eileen Williams-Esdaile: And I serve as the survivor coordinator. So a lot of times when someone may call the Sisters' Journey number, those calls get filtered to me. But because, you know, I haven't experienced everything cancer-related, what I do is I try to match the caller up with someone who's going through something similar and let them talk about it. And then I definitely encourage them to come to the support group meeting. Dr. Winer: And what kind of support are you able to provide to people when they're going through that treatment itself? I mean, because, you know, as it was for you, maybe it's a little less scary today. Maybe it isn't. I'm not sure that we've managed to eliminate the anxiety and fear that accompanies breast cancer for many, many women. But what do you do to help people who are newly diagnosed?

Eileen Williams-Esdaile: Well, we listen to them first and foremost. And what I try to do—or we try to do—is to encourage them to advocate for themselves, to not be afraid of, you know, challenging their provider. And if they're not comfortable, going to get a second opinion, recording it, bringing someone with them. And a lot of times they just want prayer, and that's what we do. Or we'll send them a care package. Sometimes they may need one of us to attend one of their appointments with them, and that's what we try to do. Whatever they need, we try to meet it.

Dr. Winer: Yeah. And so if somebody wants a member of Sisters' Journey to go along on the appointments, that's something that you can do?

Eileen Williams-Esdaile: Yes.

Dr. Winer: Yeah, no, I think that that is often very important. You know, it is often the case that when someone has a new diagnosis, that they sit and, you know, a doctor or nurse or whoever is in the room will, you know, explain the situation. But I think that there's a paralysis that occurs, and it's oftentimes

hard for people to ask questions because it's not just dealing with the new diagnosis.

Eileen Williams-Esdaile: Right. Because a lot of times, once they hear those words, "You have cancer," everything else—it goes out of your head. You just can't think about anything else. And when you said about whether the anxiety ever goes away, for me, I'll say no. I may be able to deal with it a little differently because I was diagnosed twice, and I've done genetic testing twice, and I don't carry the gene. I have no family history. So it's this, "Where did it come from?" thing. And then every time you have another ache and pain or a cough or whatever, the first thing that pops into your mind, whether you say it or not, is, "What's going on? Is this back?"

Dr. Winer: Yeah, no, I understand. And when was the second time you had breast cancer?

Eileen Williams-Esdaile: In 2012.

Dr. Winer: And was that experience any different from the first time? Was it easier? Was it harder?

Eileen Williams-Esdaile: Honestly, I think it was a little—it was scarier only because I honestly didn't know where this was coming from yet again, and the treatment was totally different. I didn't have to do radiation or chemo. I just had to take the anastrozole.

Dr. Winer: But it's still like, "Where is it coming from?"

Eileen Williams-Esdaile: Exactly.

Dr. Winer: And did you have a lumpectomy that time too?

Eileen Williams-Esdaile: No, actually, it was found—I was doing pre-op testing for a double mastectomy. I was going to get implants. And when they put—I had to have a tissue expander put in on the side that I had radiation years ago. And during the time that the tissue expander was in, I came down with a case of shingles, and they settled right in the incision. So we had to take all that out. And then at that point, that's when I started—my sister-in-law, who was an oncologist at the time, we started doing this research to try to find out what my options were. And we came up with doing the deep flap.

Dr. Winer: And so it was in that setting that we had something going on with the second diagnosis. Well, we're going to have to take just a brief break. We'll be back in a minute. Again, this is Eric Winer for Yale Cancer Answers. And we'll be back with Eileen Williams-Esdaile, our guest from Sisters' Journey. And we're going to focus down a little bit more on some of the facts associated with breast cancer in black American women and some of the challenges that we have there still in terms of treatment and in terms of some of the statistics that we find all too concerning. We'll be right back.

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Cancer Hospital, where patients diagnosed with pancreatic cancer are provided easy access to specialized care, including innovative treatments and clinical trials. Learn more at SmilowCancerHospital.org. The American Cancer Society estimates that nearly 150,000 people in the U.S. will be diagnosed with colorectal cancer this year alone. When detected early, colorectal cancer is easily treated and highly curable, and men and women over the age of 45 should have regular colonoscopies to screen for the disease. Patients with colorectal cancer have more hope than ever before, thanks to increased access to advanced therapies and specialized care. Clinical trials are currently underway at federally designated comprehensive cancer centers, such as Yale Cancer Center and Smilow Cancer Hospital, to test innovative new treatments for colorectal cancer. Tumor gene analysis has helped improve management of colorectal cancer by identifying the patients most likely to benefit from chemotherapy and newer targeted agents, resulting in more patient-specific treatment. More information is available at YaleCancerCenter.org. You're listening to Connecticut Public Radio.

Dr. Winer: Welcome back to Yale Cancer Answers. Although it is already November, we just finished Breast Cancer Awareness Month in October, and it seems appropriate to still talk about breast cancer. And tonight, I have on Eileen Williams-Esdaile, who is a member of the board of Sisters' Journey, a faith-based organization that is focused entirely on the breast cancer experience for women of color, particularly women who are Black or African-American. Dr. Winer: Eileen, welcome back again to the second half. I want to talk more about breast cancer in Black American women. Over the years, there has been tremendous progress in breast cancer. We have new treatments available. There have been improvements in survival, and that's really been seen across the board in all different subtypes of breast cancer. And it has been seen both in white women as well as in women of color. Dr. Winer: That said, women who are Black or African-American still face substantially higher risks of dying from breast cancer than women who are white. And if you are a 20-year-old Black American woman, you have twice the chance of a 20-year-old white American woman of dying from breast cancer before the age of 50. And overall, there's approximately a 40% higher chance of dying from breast cancer once you're diagnosed if you are Black versus white. And this, of course, is something that is extraordinarily concerning, I think, to everyone—certainly to breast cancer doctors and breast cancer patients. Dr. Winer: Eileen, when you hear all that, what does that make you think? Eileen Williams-Esdaile: It's apparent that it's not a one-size-fits-all disease. And I know based on my own doctors and my own experience, there's a lot of that that doesn't resonate with me. But I know from talking to other people that is truly a concern. And what we, like I said, what we try to do is help them push the envelope and get the questions answered that they need answered. Eileen Williams-Esdaile: I push clinical trials because I tell them they can't work on a cure and other courses of treatment for us if we're not part of the testing. So I'm all for clinical trials, and we try to stress that. We have our support group meetings, especially when someone brings up

the question about whether or not they should or should not become a part of it. Eileen Williams-Esdaile: And it's another reason why I know for myself and for Dawn that we were grateful to be a part of the CAB because, as I said, we need a seat at the table. Dr. Winer: Can I just explain to people what the CAB is? Eileen Williams-Esdaile: Oh, I'm sorry. Dr. Winer: No, it's okay. The CAB is the Community Advisory Board that the Cancer Center has. And both Eileen and her colleague Dawn in Sisters' Journey are both members of it. Keep going. Eileen Williams-Esdaile: Just to get that firsthand information, to make relationships with all of the people associated with CAB. It opens us up to more, better insight, and we can better equip our survivors with information. And as things come up, you know, we like to participate and try to get as much information as we can so we can bring it back to the group and share it with them. Dr. Winer: Yes. No, I think this is incredibly important. Of course, you know, many people have spent a lot of time trying to understand why it is that American Black women die from breast cancer once they have it at a much higher rate than white women. And I don't think there's any single answer. Dr. Winer: I will say that I think much of this relates to access to care and inadequate access to care. I think some of it is also about the care at times not feeling comfortable to everyone in the same way. And when you're someone who comes in and all you see are a lot of white doctors, and you're a woman from a different background, I think that it may be harder to form the kinds of relationships you need. And, you know, this worries all of us. Dr. Winer: I will also say that there have been people who have said that maybe there's something different about cancers that arise in women who are Black. And in particular, there seems to be a higher incidence of what are called triple-negative cancers. My own hunch, although I don't know this for sure, is that that has nothing to do with the genes that we're born with. And it might have to do with exposures early in life. But of course, this is still a very important area of research. Dr. Winer: But I don't know, I personally feel like this is a real urgency in terms of cancer research and cancer treatment. And the fact that we have a group of patients who are doing so much worse than many others is a big red flag to me and says we have to really invest in this area. Eileen Williams-Esdaile: Absolutely. Dr. Winer: Tell me though, because, you know, one always wonders how easy it is to fix any of these problems, but it has struck me that access to care, in the ideal world, is something we should be able to fix. But what do you and other members of Sisters' Journey feel about the experience of coming in for care as a Black woman walking into the institutions across the state? Eileen Williams-Esdaile: You know, I can only base this on responses I've gotten from a lot of our membership because, like I said, my experiences—I really haven't had any negative experiences. Eileen Williams-Esdaile: You know, I can only base this on responses I've gotten from a lot of our membership because, like I said, my experiences—I really haven't had any negative experiences. And I know, like, even my primary care physician, for one, he's very—he wanted our trifolds to put into his office, and he actually called just recently for me to send him some more because he's really trying to push Sisters' Journey to his patients, and I really appreciated that. Eileen

Williams-Esdaile: You bet. He purchases our calendars, and he passes them out to his staff, and a lot of them are Caucasian, but still, he passes them out. He has them up in his offices and everything. And I'm just trying to get that type of exposure. But I know a lot of women, they just feel like they either get talked down to or a lot of the things that are offered to a Caucasian woman are not offered to them. Eileen Williams-Esdaile: But then again, if a lot of people aren't strong enough or don't know how to navigate for themselves or to ask these certain questions… But that's why I said, while we come to all these seminars and symposiums and conferences and stuff, all the information that we get, we try to filter back to them so that they can try to advocate for themselves or have us help them navigate through their own health care. Because a lot of them realize that that's what they need to do, but it's not easy for them to do it. Dr. Winer: Don't you think that we as doctors and nurses and others also have to make special efforts to reach out and be our patients' best advocates? Eileen Williams-Esdaile: Absolutely. Absolutely. I mean, a lot of times, you know, some doctors, they'll—it's a job to them and that's it. And then some gray area loses the compassion for the person. And I know one of my daughter's friends was just diagnosed a couple of weeks ago at age 31 as well. And she fortunately has—when she told me who her providers were, I said, "Well, you're in good hands because I respect both of them highly." Eileen Williams-Esdaile: And she, so far, she's doing well. And what I admire about her is because she's young, she's taken to social media, and she made these reels of when she went and had her mammogram, when she went and had her port put in, when she started her first chemo last week. So she's educating her peers. And just within that alone, that got my daughter to go and get her first mammogram done because I've been trying to get her to go since she was 27, and she's now 31. But she just went three weeks ago. Dr. Winer: Yeah. Well, you talk about, at times, hearing that people feel like they're either being talked down to or they're not being offered quite the same, perhaps, options. You know, you talked earlier about clinical trials. And what we know about clinical trials is that there are far fewer people of color who participate in clinical trials than people who are white. But the biggest problem is often that they're not offered clinical trials, right? It's not that they turn them down. Dr. Winer: And this is true of people of color; it's also true of older patients who are often not offered clinical trials either. But it's really—I think that the medical community has to get better. Eileen Williams-Esdaile: Yeah. Dr. Winer: Yeah. I'm totally with you. And I think that came up during one of our CAB sessions not that long ago. Dr. Winer: And, of course, the other fact in our society is that really across the board, in virtually all health conditions, the outcomes for people who are of color—in particular women and men who are Black—just are not the same as they are for white individuals. Dr. Winer: We see this across all cancers. And as I'm sure you know, and many of—if not all of—our listeners know, maternal-fetal outcomes for women who are Black are also not nearly what they should be. And this has, of course, led many people to speculate whether racism is playing some role in all of this. And, you know, years of discrimination and prejudice and what that does in terms of leading to stress. But it's clearly something we

have to work on.

WNPR Radio Voice: That was Eileen Williams-Esdaile, a board member and survivorship and event coordinator for Sisters' Journey. If you have questions, the address is canceranswers@yale.edu, and past editions of the program are available in audio and written form at YaleCancerCenter.org. We hope you'll join us next time to learn more about the fight against cancer. Funding for Yale Cancer Answers is provided by Smilow Cancer Hospital.