

An Interview with Vicky Cooke

The Former Executive Director of the Delaware Breast Cancer Coalition

Timothy E. Gibbs, MPH, NPMc

Vicky Cooke is the former Executive Director of the Delaware Breast Cancer Coalition, Inc. (DBCC). She retired in January 2017 after a laudable career with over 45 years of non-profit management and program development experience. As a two-time breast cancer survivor, Vicky spent much of her career as an advocate on behalf of breast cancer issues in Delaware. She served as a volunteer board member of DBCC for five years, helping to raise funds and serving as a spokesperson for the organization's grassroots projects. In 2000, Vicky was hired as DBCC's first Executive Director and expanded the agency to a statewide organization developing programs and services that address the breast cancer needs of women and men in Delaware and the tri-state region. From breaking down barriers to mammography screening to helping to support a newly diagnosed patient, Vicky was and continues to be an engaged and highly dedicated community member.

She attended the University of Delaware and Villanova University. She is a former member of the National Breast Cancer Coalition's Board of Directors and a graduate of NBCC's Project LEAD and Clinical Trials LEAD. Vicky served and continues to serve on many community coalitions including the Delaware's Cancer Consortium, Highmark's BluePrints for the Community Advisory Council, and various local cancer agency boards. While she is now retired, she has agreed to chair the Delaware Breast Cancer Coalition's Sussex County Association. Vicky is the mother of three grown daughters, has nine grandchildren, and a dog named Maggie.

In June 2017, Vicky was awarded the inaugural Victoria Cooke Leadership Award for her vision and direction at the Coalition. She has offered incredible support and leadership to so many survivors, members of the medical community, business leaders, and friends with distinguished grace and humility. Subsequent award recipients will be recognized for their years of service, support of breast cancer survivorship, leadership in healthcare delivery and research, generous philanthropy, and cultivation of businesses in the fight against breast cancer.

TG: What got you into this work?

VC: My career started in non-profits, with Girls Incorporated, and I was very much an advocate for issues for young girls and young women. When I was diagnosed with breast cancer, and I was working at Girls Inc., I had an opportunity come along at the Delaware Breast Cancer Coalition, when it was just a grassroots organization. Being a survivor, you have a great sense of wanting to give back to the community and to share your experience. It becomes a sisterhood with other survivors where you don't want other survivors to experience what you've experienced. So I got involved with DCBB as a volunteer; I did a lot of the fundraising and helped them get things off the ground. It grew and got to the point where they needed an Executive Director.

Based on my non-profit experience, I was asked to be the Director (see Figure 1), and I had already worked with them for 5 years as a volunteer. I was coming on to work as a new Director for an organization that had only done some fundraising, so when I started we immediately identified what some of the needs were in Delaware.

I was diagnosed [with breast cancer] when I was 44 and that was considered to be a young woman. So we started a program that was called the Young Survivors in Action because there were an alarming number of younger women being diagnosed. Breast cancer wasn't just a disease affecting your mother and grandmother; it was affecting younger women as well. That was one of the first programs we developed and submitted a grant proposal for, which got funded, and we then started to partner with the State of Delaware. They were looking for outreach people who would go out and identify women that needed mammograms. Little by little, we were able to get some contracts, while also performing a service, and creating some program delivery. From there, we grew the agency to be Delaware's most trusted resource for breast cancer.

Figure 1. Tim Gibbs, Vicky Cooke, and new Delaware Breast Cancer Coalition Executive Director, Eileen Filliben Edmunds



I like to say our programs now form a circle. We go out and we try to identify women who need to be screened, and we educate them about risk. There is no prevention for breast cancer, but you can reduce your risk through things like maintaining a healthy lifestyle. We have a strong outreach program, if someone needs to be screened, we can screen them in our mammography van. If someone gets diagnosed on the van, or elsewhere, then we have program that helps them through their breast cancer journey, and that is our peer mentoring program. This program connects women with similar circumstances and needs, and their mentor can help them through their journey. Some people may have more than one mentor depending on their treatment and other factors.

We also educate the public about the newest advancements in breast cancer through our breast cancer update, which will happen in April. It's free for the public and every year about 300 to

400 people attend. We have medical professionals and researchers presenting during this one-day symposium. We also encourage advocacy. If you've been diagnosed or breast cancer is something that you feel strongly about then we have advocacy efforts as well...it's a full circle of service and delivery to the community.

TG: What educational background did you have?

VC: I have no medical background at all...I went to the University of Delaware and Villanova...I think what positioned me for this job was my work in the non-profit community. If someone were to come into this new director role in this organization with a medical background, it would've looked completely different than it looks today. It's that non-profit experience, it is understanding advocacy and working on a cause that has been helpful.

TG: What changes have you seen, whether these are changes in technology or changes in crowd attitudes, with self-exams, and getting mammographies over the past 25 years?

VC: I would say over the last 24 years since I've been diagnosed, not enough change has been made. We have better treatment and better screening, but we still have the ability to end this disease. Maybe there is a specific prevention, or there is there a vaccine, like the vaccine for cervical cancer, that could end one of these types of breast cancer. People don't die of a breast cancer tumor, people die of metastasis. How do find out how to control metastasis, and how do we end the cancer metastasizing? All of this is political. It's system changes that need to be made in the research community. Even research that fails is as important as research that succeeds...but there are politics in research that keep things from moving along. You may have a young researcher with a really good idea, but the politics of research might prevent this young researcher from having an avenue to put this idea out there...as people in the community and those affected by the disease, we need to think about where are these dollars going, where is this peer review, where is the reporting, where is the reporting done, where are the consumers on the IRBs, and what is the representation of survivors in the research community.

Is the mortality rate lower? Absolutely, I have been diagnosed twice, and I sit here like I have never had the disease at all. Even people who have been diagnosed at later stages and live with metastasis, for some it has just become living with a chronic disease. My husband had diabetes, and to me the diabetes was scarier than the breast cancer because you couldn't control it. We have made progress to a certain extent, but when you look at the millions, probably billions of dollars that have been spent on this disease, and to only be where we are 24 years later, it's discouraging. And, if I had to sit here 20 years later having this same conversation, how sad would that be? With all of our progress and technology...what's behind this that we don't have figured out?

...there are still way too many people being diagnosed. In some cases this could be because there is better protection and ways of finding breast cancer earlier. Reducing health risks certainly gives you a better chance of going through treatment and living a full, regular life after breast cancer. Again, when I was diagnosed, it was still considered sort of a death sentence. I remember coming into work and having to show them I was ok. The other progress that was made was with having a lumpectomy. I had a lumpectomy; I didn't have to have a mastectomy. But before that, everyone had a mastectomy, and in some cases terrible, radical mastectomies, probably for people who had estrogen positive breast cancer, that was a lump that could've been removed. So

in that sense, we have made progress, but is that the only kind of progress we want to make? I think women, family, and loved ones all deserve more.

TG: Over the last 20 to 30 years, longevity has increased dramatically. Is there an age point at which the intervention and treatment are worse than just living out your days? For example, would a woman in her 90's go through with treatment?

VC: Probably, she wouldn't go through with this treatment because they would determine the aggressiveness of the tumor, and in somebody 90 years old, it might not be that aggressive. So with someone y older, they would look at the diagnosis and say this is a slow-growing, non-aggressive tumor and then they may possibly do some radiation. However, if they were 90 and they did have somewhat of an aggressive tumor, it would depend on their health and if they could even withstand a breast cancer treatment...you have to look at the quality of life. If you're 90, 80, or even 70, it depends on the aggressiveness of the cancer, and on quality of life. Some of that would be a very personal decision, and some of that would be a recommendation based on age and health, and I think that goes for any cancer, not just breast cancer.

TG: In other types of cancer, for example, prostate cancer in men, there have been some considerable changes in terms of the guidelines for screening. Have there been similar changes with breast cancer?

VC: There have, and we follow the [Delaware] cancer consortium's recommendations. We still say that women over 40 should get an annual mammogram. If you need a mammogram earlier than that based on your family history, then that is something to talk to your doctor about. I was diagnosed at 44 and I have 3 daughters. Their doctors all recommended they get a baseline mammogram at the age of 34. Often they suggest screening ten years before [your relative's] diagnosis when the relationship is that close. We've made such great progress with mammography, and colorectal cancer screening as well. Even history of breast cancer in a man's family should be revealed to his physician as well.

TG: What about breast cancer in men?

VC: Well it's only 1%, and usually there is a family history of some sort. The doctors can speak to that better than I can, but it doesn't affect men randomly the way it does women...usually breast cancer in men has a genetic link. To clarify, when I refer to breast cancer in women, I am including the knowledge that it does affect men, although it's such a small number.

And I should note, our programs certainly would cater to men as well should they be interested. For a while, we had an alarming number of men involved for the size of our state. We had about 10 or 11 men involved with us and that just seemed like a high number in Delaware. That was just who we knew, I'm sure there were others we didn't know as well.

TG: Can you tell me about some of the disparities- whether they are racial, socioeconomic, gender based- is Delaware in a good position in terms of screening everyone that needs to be screened, or are there subset populations that need more attention and outreach?

VC: Well, I would say organizations like ours have really focused on screening the underserved. We want to be culturally competent and we want to serve everyone who needs to be served, and we pride ourselves in that respect. Our staff represents people in the community. When we go

out and do outreach, we really have had success getting into different communities. I will say, at this point we have broken down many barriers. It's not just the Delaware Breast Cancer Coalition, it's the partners, and it is understanding the culture of a community. We have seen that African American women are better at getting screenings than white women. Many white women will put off their screenings, while African American women have heard the message, so we've made great progress with that community. We've made great progress with the Hispanic community, we have Spanish speaking staff who will do everything from calling, to making appointments, following up, greeting women, and getting them on the van [for screening] (see figure 2).

Figure 2. The Women's Health Screenings Van



Our retention of women and the showing up rate is strong because we have Spanish-speaking staff who can interpret for them, so we've done a good job, along with other people, of meeting the needs of the community of those populations. We're also in the process of hopefully hiring a woman who will do outreach for us in Sussex county with the Haitian population, which is growing in Sussex county and Dover. Haitians are moving into this state in high numbers from other states... so we are going to take a leadership role in breaking through the Haitian community. This is something we have done anyway with different populations. We're a little different than we were 17 years ago when I first started in that we aren't just about getting women screened, or just about providing some services to women who've been diagnosed, we look at women who are diagnosed and understand they have all this stuff going on in their life, good or bad, and now you just put breast cancer on top of it.

So now you've just complicated everything in their lives, but there are still many other things going on underneath the breast cancer, and it's important to remember those are still there. I think because of my non-profit background I've developed the understanding about why it's important to partner with, and be involved in, the non-profit community and with other social services. We often need to refer people out for the other issues they have, whether it is a single mom, or somebody who needs financial assistance. Right now we're helping a woman who is homeless. She's able to live with her daughter, but she has some belongings and she needs somebody to help her pay for a storage unit. If not, she has no place to put these belongings and would lose everything in addition to going through a breast cancer journey...I could tell you stories that would just break your heart about people who need things. So when you ask about

working with different communities, we work with the uninsured, underserved, all the people who would need services like ours, but we also refer them out when necessary.

TG: Two other communities I wanted to ask about include the Asian community, in particular in Hockessin, and then the lesbian community. We frequently hear about health challenges and disparities in the gay and lesbian communities being disproportionate. What the position on that?

VC: We have a great relationship with Camp Rehoboth and the different organizations in the Rehoboth area. They've embraced us and they've even raised funds for us. We've got a good relationship, but it is hard to break into the community...I think it's better than it used to be before. I think people didn't want to come out and tell you, and there was stigma, a lot of that has diminished. I think people are so much more accepting now. Our organization is very accepting and always has been. Breast cancer doesn't discriminate, and everyone who needs help deserves to have that help. We have really reached out to make sure the lesbian community to make sure they know about getting screened. We used to do the "removing the barriers" program, and do workshops...we have members of our staff that are lesbian, and again it's because we want to project the image that we are inclusive. We want our faces to be the faces of the community.

TG: You mentioned 'image' which is a perfect transition to another question I have. Through the television, the hallmark movies, there are enough stories out there that tell us having a mastectomy is a life changing challenge in terms of self-image. From your perspective as an individual, what is the reality behind that? How many women really struggle post double radical mastectomy with their image, or with how their partner sees them? How much of that is the real stuff versus what we've been?

VC: It's more than just the fact that you've had your breasts removed, it's also the fact you've been diagnosed with a disease that could be life threatening, all of that will affect someone. The image part, people will address, and certainly struggle. However, there is also phenomenal plastic surgery out there right now and reconstruction efforts, there is something that pretty much fits everyone's needs...although not everybody needs that.

I've been diagnosed twice. I had a lumpectomy the first time. It wasn't too terribly disfiguring, and I lived with it, and my husband didn't care...I by rights, and by law, am entitled some sort of reconstruction if I choose to have it. So when I was diagnosed two years ago- this is sort of a new development- they are finding women who were diagnosed with estrogen positive breast cancer years ago are sometimes re-diagnosed. It's a brand new diagnosis, and it's not the result of having breast cancer before...so I have now had it twice...I prepared myself and asked my staff what do I need to know. I had already determined what surgery I was going to have and I walked into my doctor's office and asked about reconstruction, and she looked at me and said, why would you do that? I said because I've been diagnosed for the second time, and this is what I need to do. She said back I just needed a lumpectomy.

But, there will be people who will think more is better. They may go into the doctor's office and say I want a double mastectomy, I don't even want to deal with this again, but that's no guarantee. Your breast tissue goes from your shoulder to your waist. You can cut off the fatty parts of your body, but that doesn't necessarily mean that you're cured and that's the end. So I think a person being open to what they need really is important. So if your doctor says I think

you need a lumpectomy, then consider it. It's personal choice, but consider it. If you want you could have a prophylactic mastectomy like Angelina Jolie, and there is the BRCA gene [to consider], there are other cancers...all I can say is it's important to sit down with the doctor and talk about your needs, and get second opinions.

TG: What can you tell me about Pinkwashing?

VC: So, that is one of our advocacy points. You have to look at what's really happening out there. [Pinkwashing] is when companies have capitalized on a disease, and I'll use the example of M&M's. M&M's came out with these pink and white candies for breast cancer awareness and they said they were going to donate a dollar to breast cancer for each bag sold. So did they really give a dollar? They really just raised the price of a normal bag of M&M's and then gave a dollar. Somebody who buys a pink mixer for example, because the manufacturer says they'll give \$25 to breast cancer if you buy the pink mixer, should just give \$25 directly to the cause instead having the money go to a company trying to make money. Companies have made so much money off of breast cancer. If you look around we're not a real "pink" organization...People have gotten so caught up with wearing pink but there's so much more to it.

TG: What impact, if any, from a positive standpoint, did the Affordable Care Act have for the population that DBCC works with (screening, prevention, treatment, etc.)? And, if the new administration in Washington makes significant changes to the ACA, what fears do you have on how it will impact the clients?

VC: I'm not sure about the ACA and the impact it had on the people we serve, but first of all, in Delaware we have such great cancer support medically, through programs like the cancer treatment program. If someone is underserved or under-insured, they can go through the Screening for Life program, and they're guaranteed screening. Anybody in Delaware can be screened. The ACA hasn't had an impact on who can be screened.

I would say there is no excuse for someone not to be screened; the money is available one way or another. Getting a mammogram isn't an issue. If you were underserved and you were diagnosed with cancer and you're in the cancer treatment program, you're guaranteed treatment for 2 years. So Delaware has that covered...what we did see was people with insurance, and their deductible was so high, their co-pay was high, their premium was high, they had insurance but couldn't afford to be treated. And I can't tell you how many women came through this organization needing financial assistance because they couldn't afford to be treated while they had insurance. That isn't something that's being talked about...now I will also say that I don't know anyone in the state who was turned away for any reason. Whether that was with the help hospitals and the doctors being accommodating, or organizations like ours helping pick up some of the financial assistance...but [cost] is still a huge problem for those with insurance and that to me is a huge issue.