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Breast Cancer Advocacy and Public Policy

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Speech:[†] Breast Cancer Advocacy and Public Policy

Frances M. Visco^{*}

I. INTRODUCTION

There is no better illustration of the intersection between law, politics and social justice than in the world of women's health care advocacy. I was honored to have the opportunity to participate in this year's Public Interest Law Speakers Series to explain how my law training enhanced my career in breast cancer advocacy. This training enabled me to work to change the law, instead of merely working within it.

The issue of breast cancer, and women's health generally, is a political issue and requires an expanded approach to public interest law. Decisions that affect how individual women are treated—such as how much and what research is performed, whether the environmental connections to breast cancer are understood and dealt with, whether all women will have access to quality health care—are made at the political level. Appropriations for breast cancer research come from Congress. Congress tells the Food and Drug Administration (FDA) what to do, and the FDA approves drugs and devices.² Government-regulated programs, such as Medicaid and Medicare, provide access to health care for many individuals in this country. Even private insurance companies are regulated by the states.

[†] Delivered at Washington University School of Law on February 16, 2005. Minimal footnotes have been added by the author.

^{*} Antitrust attorney and partner in a Philadelphia law firm until diagnosed with breast cancer seventeen years ago, she was named president of the National Breast Cancer Coalition in 1991, the first and only person to hold this position. This Article is based on a presentation by Ms. Visco in the Public Interest Law Speaker Series at Washington University School of Law on February 16, 2005. She wishes to acknowledge Romi Neustadt, J.D., for her assistance with this Article.

2. Food, Drug and Cosmetic Act, 21 U.S.C. §§ 301–97 (2000).

As a lawyer, I recognize that to have a significant impact on breast cancer—not just for individual women but on the systems that affect all women—the usual public interest law approach is not enough. Necessary, overarching change will not likely come about through the judicial system, a system that is bound by tradition and precedent. What breast cancer advocates realized in the early 1990s was the need to make new law to change the systems that affect everyone—the systems of research, access to care and regulation. Fortunately, my background and education equipped me to meet the challenges of forging new law and refusing to settle for the status quo in the name of precedent.

II. MY ROAD TO WOMEN’S HEALTH CARE ADVOCACY

I have always been a political person interested in social justice. My first memory of what I wanted to pursue professionally was to become a medical missionary. Soon thereafter I decided I wanted to be a lawyer in order to right wrongs. While I worked my way through my undergraduate degree and law school, I actively volunteered for causes that were important to me. I was an anti-war activist in the 60s and early 70s and fought for women’s rights. And I have always regretted that I was born too late to be part of the peak of the civil rights movement.

I went to law school somewhat late in life, at age thirty-two, and graduated in 1983. After many years focusing on issues of social justice, I went to work for a Philadelphia law firm in the commercial litigation department. I did so, however, because I knew I would have a mentor at the firm who volunteered time with the ACLU and had been involved in death penalty cases before the U.S. Supreme Court. My true mentor in the firm turned out to be another partner who taught me how to use the law to logically construct and prove a case, step-by-step; to tear it apart and then build it back up. Because of him I learned the importance of believing in your case, and that the focus should never be on my performance, but on the client and the client’s goals. Because of him, I learned that I should never walk into a courtroom without knowing every strength and weakness of my case, or every possible argument and rebuttal my opponent could make. While I knew I was receiving invaluable tools for my litigation

toolbox, I had no idea how truly indispensable this training would prove in my future role as a health care advocate.

I might still be a partner in that law firm, handling antitrust litigation, sitting on nonprofit boards in my community and volunteering for political campaigns. But in September 1987, at the age of thirty-nine with a fourteen-month-old son, I was diagnosed with breast cancer. Between September and May of 1988, I underwent treatment—surgery, radiation and chemotherapy. I cut back slightly on my caseload and put my volunteer work on hold. When I went back to practice law in full force, I began to work with a local breast cancer group in Philadelphia. While the group filled the important role of helping individual women, I wanted to challenge the systems of research and care and become politically involved.

Fortunately, in 1991, I was invited to a meeting that launched what was to become the National Breast Cancer Coalition (NBCC). The meeting gathered together a group of women who, like me, had been activists for other causes. We wanted to do for breast cancer what AIDS activists had done for AIDS.

As an attorney on the first board of advisors to NBCC, the group initially looked to me for the typical role of lawyers on nonprofit boards such as advice in structuring the organization and incorporation. In addition, I was also able to bring to the discussion the framework that I had come to embrace when dealing with any case or cause: identifying the goal—how to define success—and then the step-by-step approach of building toward that ultimate goal by building an argument to sway the decision makers and making certain that you have the evidence to back it up.

When I first started to receive calls from women around the country asking me to run for the position of the first president of NBCC, I remember telling them that I could not do it. I had a full practice and was just a volunteer. But they kept asking and finally I said what seems in retrospect the most ridiculous thing that I have ever uttered: “Okay, I will do it if you promise it will not interfere with my law practice.” Naturally, it took over my life. While I gradually convinced my partners that I could work part-time, ultimately they told me I had to make a choice—either come back as a full-time partner, or leave and run NBCC. In April 1995, I resigned my partnership.

III. THE LAWYER'S BAG OF TRICKS: USING LITIGATION SKILLS TO BUILD THE NATIONAL BREAST CANCER COALITION

I was not giving up the law; rather, I was changing how I would work with it. I went from working within the judicial system—trying cases and representing individuals in class actions—to using the legislative and regulatory aspects of the law to change public policy and make law. I viewed breast cancer not as an individual fight or an individual health issue, but as a vital issue in the women's health arena that had been ignored by the powers-that-be for too long. Breast cancer was a new social justice challenge that needed legal attention.

I had sat in a conference room with a team from my law firm many times, laying out the elements of my client's case. How would we define success? What did we need to prove to achieve our victory? What were the required steps, the necessary testimony and documentary evidence, and how would we assure that it would all be admissible? My legal training brought that same process and analysis to NBCC.

We decided to define success as eradicating breast cancer. Yet, we did not know how to prevent breast cancer, how to detect it early enough, or how to cure it. What we did know was that to achieve success we had to focus on the systems of research and access to care. We had to make certain that we understood how to prevent and treat the disease. We also needed to ensure that all women had access to what was available. Of course, we needed increased funding for all of this.

As breast cancer advocates, like trial attorneys, we needed to prove our case. To do so, it was imperative to determine what the decision-makers cared about. We did this by employing the skills learned from my litigation practice and my mentor. Through an analytical approach, we took apart each issue and reconstructed it, carefully considering every component, thinking critically, constantly questioning and considering how all the pieces fit together. We were relentless and courageous, took nothing at face value and questioned everyone's motives and agendas. We knew that presenting our position with force and credibility would make others want to follow.

To reach our goal of eradicating breast cancer, we had to make certain the research community had the necessary funds. We critically analyzed the research funding problem. Was more money actually needed or were adequate funds simply being allocated incorrectly? What would the right amount of money be, how could we find out, and who should we believe? While researchers will always tell you they need more money, the government typically argues that they are already getting enough. NBCC determined that to get the real answers to these questions and prove our case, we needed to do independent research and analysis and conduct our own research hearings.

Based on this research, we determined that in 1992 the scientific community could spend an additional \$300 million on breast cancer research—from its current level of \$100 million to more than \$400 million.³ Congress did not embrace us or our numbers with open arms. While we knew it would take more than evidence to sway the decision-makers, we also understood that pressure from their constituents could force change. Accordingly, we began to grow and energize our national grassroots network.

That was also the year I had my first opportunity to testify before Congress.⁴ I remember the day vividly. It was what I called “Disease Day” before the Senate Committee on Appropriations, and there were many people in line waiting to testify about their particular organization and why Congress should give them more money. I was the last in line.

Each group made its plea. The messages were basically all the same: “We really appreciate what you have done for us in the past. Thank you so very much. If you could see your way through, we’d really appreciate it if you could give us a little more money this year.” I was not impressed.

During the others’ testimony, I sat in the back of the room and listened intently. Looking around, I saw many breast cancer survivors in attendance, waiting anxiously. This was the monumental beginning

3. *Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations, FY 93: Hearing Before the S. Comm. on Appropriations*, 102d Cong. 487-92 (1992) (statement of Frances M. Visco, President, National Breast Cancer Coalition).

4. *Id.*

of our movement. As a trained litigator, I knew I could not address the committee, hat in hand, and merely ask for money; I had to make my case, argue my position and persuade the members to change their behavior. I also needed to speak directly to the advocates in the room in order to convince them that we had chosen the correct political path. When it was finally my turn, I discarded my prepared remarks and walked up to the microphone.

"I'm here to tell you that women have declared war on breast cancer," I said. "You have found billions of dollars to fund the Persian Gulf War. You have found billions of dollars to fund and bail out the savings and loan industry, which was destroyed by men in suits. You can find \$300 million more to save women's lives. And I'm here to tell you that we won't go away until you do."⁵

While that was a call to action, it was also powerful and persuasive because we had prepared our case and could back it up. With a great deal of focus and hard work, we educated our grassroots network and trained them in not only the science of breast cancer, but also how to use the political process to be good advocates. They inundated Congress with our messages, and every year our network of advocates returns to Congress and demands continuation of funding. To date, NBCC has brought nearly two billion new dollars to breast cancer research from the defense budget alone, but that's a story for another article.

IV. FROM RESEARCH TO ACCESS TO CARE

A recent Harvard University study indicates that half of personal bankruptcies in the U.S. (two million individuals) are the result of illness or medical bills.⁶ Shockingly, three-quarters of those who declared bankruptcy had health insurance. With forty-six million Americans uninsured, the situation clearly requires a legislative fix and screams out for public interest lawyers to get involved to fix the systems of access to healthcare.⁷

5. David U. Himmelstein et al., *MarketWatch: Illness and Injury as Contributors to Bankruptcy*, HEALTH AFF. (2005), <http://www.healthaffairs.org>.

6. *Id.* (analyzing data from the Consumer Bankruptcy Project).

7. KAISER FAMILY FOUND., KAISER COMM'N ON MEDICAID AND THE UNINSURED, THE UNINSURED: A PRIMER (2004), available at <http://www.kff.org/uninsured/7216.cfm>.

At its inception, NBCC did not take on the entire health care system. Yet after we tackled the research funding issue, we turned to access to care. In 1991, we were faced with a law that Congress had passed that required the government to fund screening, mammograms and pap smears for uninsured women.⁸ These women are typically the working poor, uninsured or underinsured, with incomes at approximately 200 percent of the poverty level. Despite their low income, they earn too much to qualify for Medicaid. While the screening act would diagnose cancer, there was no provision to treat the disease if it was detected. These women were left to a rapidly deteriorating system of charity care and, while they could have gone to public interest law firms and programs for individual help, there was no law to apply and no precedent to argue.

NBCC analyzed the issue of screening for breast cancer without treatment and researched what public policy approach would be best. Logically, it appeared that moving these women into an existing system would be far superior to creating a totally new system of access. Our goal was to construct legislation that would make these women eligible for Medicaid for all of their health care needs.

Congress responded that these women could be helped through the charity care system. Therefore, we knew we needed evidence of the extent of the problem and why reliance on charity care was not enough. Again, we conducted independent research and analysis and presented data to Congress to prove why the charity care system was a failure, and our pressure brought about a Congressional hearing on the issue.⁹ To testify to the extent of the problem, we identified and brought in physicians who helped with charity care and patients who had been screened through the system but were not treated. We also conducted forums to educate Congress and made our case to the administration. We trained our grassroots lobbyists to understand all the possible arguments and what the answers were. Slowly, we moved the bill through the system. Finally, after more than four years, we achieved success, and today a system of care for thousands

8. The Breast and Cervical Cancer Mortality Prevention Act of 1990, Pub. L. No. 101-354, 104 Stat. 409.

9. The Breast and Cervical Cancer Prevention and Treatment Act of 1999, H.R. 1070, 106th Cong. (1999).

of uninsured women in this country exists through legislation in the public interest—all because of grassroots advocacy.¹⁰

There are constant assaults on the public interest that take many forms, and NBCC, like any advocacy group, cannot afford to lose focus. For example, decision-makers will often appear to devise a right in response to advocacy, but it will be devoid of a remedy. It happens more and more as issues such as tort reform get more attention. When we tackled the issue of genetic discrimination, we had to deal with this exact problem.

We were working on a national level to have a law introduced that would protect all individuals from genetic discrimination on the basis of predisposition to disease. On a state-by-state basis, our advocates were working to get state laws passed that would prohibit this discrimination in health insurance and employment. Our group in Virginia was incredibly proud of a bill enacted in that state that would actually afford those protections.¹¹ When we looked at the legislation on the national level, however, we realized that there were no enforcement provisions, so there was no way to give the legislation true meaning.

Accordingly, we began developing policies of inclusion of enforcement provisions in all legislation that we supported. We educated our grassroots advocates around the country about the importance of that approach, and made certain that all of the laws that they were working on in their respective states contained strong enforcement provisions. It is this type of focus that NBCC has brought to advocacy and grassroots efforts, in large part, I believe, because of my legal background and the background of other leaders in this movement.

I have testified before Congress a number of times on the need for meaningful enforcement in any legislation that confers rights. One of my favorite occasions was an invitation by the House Commerce Subcommittee on Health and Environment to testify at a hearing entitled *Barriers of Access to Quality Care for Patients* that covered tort reform and malpractice caps. When I spoke, I asked the

10. The Breast and Cervical Cancer Prevention and Treatment Act of 2000, Pub. L. No. 106-354, 114 Stat. 1381.

11. Genetic Information Privacy Act, VA. CODE ANN. § 38.2-508.4 (2005).

subcommittee: If we are truly interested in removing barriers to access to care, why are we not speaking about guaranteeing access to health insurance and health coverage for all Americans? Why are we beginning the discussion with punishing the patients?¹²

V. THERE IS SUCH A THING AS BAD ADVOCACY

Unfortunately, bad advocacy exists. One example is a piece of legislation touted by a number of groups and individuals around the country. The “Drive-through Mastectomy Bill” that some advocates have designed would require insurance companies to cover in-hospital stays for at least forty-eight hours after a woman has had a mastectomy.¹³ It sounds very compelling, and millions of individuals have signed the petition to support the legislation. Yet it is stalled on Capitol Hill in large part because it does not have the support of NBCC.

The legislation is bad public policy, and we determined this by applying the process we honed in breast cancer advocacy to analyze the legislation. What are the goals of the legislation? Is it really needed? What is the evidence behind it? How would we define success? We quickly determined that the science does not support the mandatory hospital stay approach. Evidence from multiple studies¹⁴ has established that medical outcomes are equally good after outpatient mastectomies as after hospital stays. In addition, rather than trying to reform the health care system one benefit at a time, what we need to do is focus Congress on reforming the entire health care system.

As responsible grassroots advocates, we recognize that by critically examining these policies, we are able to see the flaws. We cannot simply react to problems defined by others. We must all

12. *Harming Patient Access to Care: The Impact of Excessive Litigation: Hearing Before the H. Comm. on Energy and Commerce*, 107th Cong. (2002) (written statement of Francis M. Visco, President, National Breast Cancer Coalition).

13. Breast Cancer Patient Protection Act of 2003, S. 1684, 108th Cong. (2003); Breast Cancer Patient Protection Act of 2003, H.R. 1886, 108th Cong. (2003).

14. Anthony A. Goodman & Armando L. Mendez, *Definitive Surgery for Breast Cancer Performed on an Outpatient Basis*, 128 ARCHIVES SURGERY 1149 (1993); Richard G. Margolese & Jean-Claude M. Lasry, *Ambulatory Surgery for Breast Cancer Patients*, 7 ANNALS SURGICAL ONCOLOGY 181, 181–87 (2000).

question and analyze what is the correct approach. NBCC has created a model that has been replicated by many other groups. Earlier this year, we were identified in a study that was published in *The Hill*, a newspaper about Congress. The study, a survey of congressional staff members conducted by a University of Chicago professor, identified NBCC as one of the top twenty groups that influence national health policy.¹⁵ The other organizations on the list were incredibly powerful, well-funded organizations, such as the American Medical Association and the Pharmaceutical Manufacturers Association of America. This is impressive recognition for our grassroots network of organizations that is barely fourteen years old. I believe we made the list because of our approach to responsible advocacy and because we have never been afraid to be controversial. Indeed, NBCC's agenda is often controversial. For example, our view that trained advocates belong in power positions and should have a seat at the table where decisions are made is controversial. But we are about change, and when you are challenging entrenched systems, there will always be controversy.

VI. CONCLUSION

While legal training is not necessary for effective public advocacy, it is an invaluable preparation. NBCC has brought billions of new dollars for breast cancer research and systems of access to care for thousands of underserved women by recognizing that breast cancer is a public interest issue. It is an issue that, with legal training and skill, we have brought to the forefront of the political agenda in this country.

Someone very dear to me, Millie Jeffrey, the Democratic activist, said shortly before her death:

I believe in individual initiative. In other words, that each of us has a responsibility to take some action as an individual in our own part. But I also know that unless that is brought together in collective action in a group working together, in a group

15. See Top 25 "Influential Groups in Health Policy" Based on Interviews with Congressional Staffers, HILL (Wash. D.C.), October 1, 2003.

agreeing on goals and objectives and then implementing those, that you are not going to produce change. And, I suppose, change is what I believed in all my life.¹⁶

We all recognize that the law is the greatest instrument for change. Regardless of the path you choose after law school, I encourage you to find a meaningful cause in which you believe and volunteer or make it part of your daily work. And remember, there are many possible paths. I am proof of that.

16. Interview by Tom Downs with Mildred Jeffrey, Political Activist, in Okemos, Mich., (1995), reprinted in Adam Bernstein, *Mildred Jeffrey, 93; Fought for Social, Political Justice*, PHILLY.COM, Mar. 29, 2004.