

**Testimony of
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House Energy and Commerce Committee
Health Subcommittee**

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Thank you, Chairman Pallone and members of the House Energy and Commerce Health Subcommittee, for the opportunity to testify at this hearing on breast cancer. I am honored to have this opportunity to appear before you. The National Breast Cancer Coalition commends your attention to breast cancer and your efforts to enact comprehensive health care reform – which is our highest legislative priority. While this hearing is examining a number of breast cancer specific bills today, I would like to focus my comments on the need for comprehensive health care reform.

I am Fran Visco, a 22-year breast cancer survivor, a wife and mother, lawyer, and President of the National Breast Cancer Coalition (NBCC). I was diagnosed at age 39 when my son David was 14 months old. As you may know, NBCC is made up of hundreds of organizations from across the country. Our Board of Directors consists of 25 of these organizations and represents the diversity that is breast cancer. These groups come together under our umbrella to focus on systems change in policy, health care and research. NBCC's mission is to eradicate breast cancer. NBCC's main goals are to increase federal funding for breast cancer research and collaborate with the scientific community to implement new models of research; improve access to high quality health care and breast cancer clinical trials for all women; and expand the influence of breast cancer advocates wherever breast cancer decisions are made.

Background

Our work is driven by the hundreds of groups that form our coalition, many of which are made up of women who have had breast cancer. We are a coalition of organizations: we are African American Women in Touch. We are Women of Color Support Group. We are the Alamo Breast Cancer Foundation, Linda Creed, SHARE Network, Nueva Vida and many, many more. We are all of these incredibly diverse groups who have come together to make the decisions on behalf of NBCC, to set the agenda, to be the National Breast Cancer Coalition.

We know that each woman's experience with this devastating disease is unique. And in 1991 when NBCC was formed, we knew that there was a need to focus on public policy, research, and the health care system outside the context of any individual's disease or health care status, and within the realm of the public good.

In order to maintain and fulfill that focus, NBCC does its homework. We thoroughly research issues before we adopt positions and to determine if they warrant attention by our committed grassroots network, who give so much to our cause. We believe in evidence, and that women and men – all of us -- deserve the truth about breast cancer and policies that are rooted in fact, research and science. We take that belief very seriously. Each year our grassroots leadership sets policy priorities to help achieve our mission to end breast cancer. We follow a comprehensive process of critical analysis of the issues, research and education of our members on the background, controversies, and pros and cons of each issue we may address. After much discussion and debate, we determine those policies NBCC will support.

We followed this process to determine that *Guaranteed Access to Quality Health Care for All* would be our number one priority. It has been the primary focus of our organization for several years now because we recognize we will not achieve our mission to end breast cancer until all women have access to the care they need. We believe that access to quality and affordable health care and access to medical treatment that is founded in scientific evidence are two of the best tools available to achieve our mission.

NBCC's Commitment to 'Guaranteed Access to Quality Care for All'

Since its inception in 1991, NBCC has known that the only way to achieve our mission to end breast cancer is to ensure guaranteed access to comprehensive, quality health care for all. After several years of research and analysis, in 2007, NBCC articulated its vision for accomplishing this goal when our grassroots board of Directors approved a *Framework for a Health Care System Guaranteeing Access to Quality Care for All* which builds on principles it adopted in 2003.

Throughout the process of developing the *Framework*, NBCC applied its longstanding commitment to advancing evidence-based medicine and training consumers to strive towards systems change. NBCC believes strongly in guaranteed access for all, educated patient participation at all levels of health system decision making, shared responsibility and benefits that are based on medical evidence and cost effectiveness so that patients can be assured of consistent, high quality healthcare. I am submitting a copy of the *NBCC Framework* for the record.

NBCC applauds the Chairman's commitment to passing a comprehensive healthcare reform bill. Specifically, NBCC's *Framework* calls for a healthcare system in which coverage is guaranteed to all individuals, and does not discriminate or deny coverage for any reason, including pre-existing conditions.

Our *Framework* also strongly supports comparative effectiveness research because we believe that it is necessary to help ensure quality, affordable healthcare for all. We need a high level of evidence for doctors and patients to choose which care is appropriate, for whom, and under what circumstances as well as who should pay for it. This is critical to patient-centered care. There are two necessary components to this evidence: the first is high quality clinical research of new

interventions and the second, and equally necessary component, is comparative effectiveness research of interventions in the real life settings all doctors and patients face. This research provides an opportunity to find these answers, in settings that reflect the situations of the average person, adding value beyond what we obtain from the highly controlled setting of traditional clinical trials.

In addition, NBCC's *Framework* calls for a significant number (25%) of educated patient/consumer members on all committees, commissions and boards involved in health care including those established to review and assess the best evidence-based treatment options, their cost effectiveness, and the appropriate level of benefits.

We commend the Committee for its work on HR 3200, America's Affordable Health Choices Act of 2009, which achieves many the benchmarks set forth in our *Framework*. NBCC was pleased to endorse H.R. 3200 and looks forward to working with you to ensure that all individuals have access to the comprehensive quality health care they deserve.

NBCC's Work to Challenge the Status Quo Using an Evidence-Based Approach

We very much appreciate your interest and support of our shared goal to save lives and end breast cancer. You have the power to make a real difference for all of us. We know how complicated these issues are, how difficult your task is. We know how complex breast cancer is and how careful we all have to be to make sure that what we are doing is the right thing in terms of women's health. There are too many unfortunate examples of policy, messaging and beliefs that have taken hold when there was in fact no real evidence behind them, and these actions resulted in harm to women.

We are all familiar with the story of *Autologous Bone Marrow Transplants* (ABMT) in treating breast cancer. The community believed more chemotherapy would be better and that transplants worked in some cancers so why not breast cancer? While clinical trials were launched, too many women received the treatment outside of the trials, the trials did not accrue and it took many more years than it should have to get the real answer. Women died from the treatment itself. NBCC said from the beginning that we needed the trials to get the answers. When we finally had the evidence, it was clear that ABMT was not better than conventional chemotherapy. And yet laws were passed in various states mandating insurance coverage of this treatment, an example of misplaced advocacy when evidence did not exist. And harm resulted.

We also know the story of *hormone replacement therapy* (HRT) becoming a widely used intervention for women based on the belief, without evidence, that it would help cardiac health among other benefits. Yet when the clinical trials were completed, we found out that HRT increased a woman's risk of breast cancer and other harms. Many many women took HRT when we had no evidence of its effectiveness and many women were harmed.

Breast self examination (BSE) falls into this category also. BSE became gospel, yet there was no evidence at all that it saved lives or found breast cancer at an earlier stage. When we did have

the evidence that, not only did it not save lives or find cancer earlier, it resulted in the harm of unnecessary biopsies and increased anxiety, the public would not believe it because the marketing of this approach had been so successful. Again, the perils of acting with no evidence when women's health is at stake.

NBCC has taken the position many times that we cannot afford to waste our limited resources and risk women's lives on medical treatments and on public health interventions that have not been shown effective, particularly when there is evidence that the intervention may be causing harm. These resources would be better spent on funding more research studies to identify interventions that really do work, such as better ways to detect, treat, and prevent breast cancer. These resources would also be better spent on interventions that have already been shown to reduce breast cancer mortality, such as access to appropriate treatment for all.

Breast Cancer Survival Rates

Let us be very careful not to make the same mistakes again. This holds true for the breast cancer bills currently pending before this committee and also holds true for health care reform. Currently, opponents of meaningful health care reform have begun to use incomplete, outdated and misleading statistics about breast cancer to support their arguments in opposition to these efforts. NBCC wants to set the record straight for the members of this Committee and for anyone else who may have come across this misleading information.

Opponents are using five year survival statistics from 1990-94 for breast cancer in England to support the claim that health care reform that includes a nationalized health care system would result in more breast cancer deaths in the United States. This is simply not true. Indeed, arguments for reform can be supported by breast cancer survival statistics from different countries: the same *Lancet* article that reported the rates for England, reported that the United States had a rate of 84%, Sweden, 82%, Canada, 83%, Australia 81%, Japan 82% and Cuba 84%. Different countries, different systems, similar survival rates. And none of it is relevant to the current debate.

Some people use "survival rates" to show progress in breast cancer, but this is not appropriate. A "survival rate" is the proportion of people diagnosed with a disease at a point in time, and who are alive at some fixed time in the future, for example in 5 years or 10 years. "Mortality rates" which compare the death rates in two groups at a specific point in time, should be used instead. Our analysis shows that the U.S. breast cancer mortality rate is indeed lower than it is in England. However, the breast cancer mortality rate in the England is falling at a faster rate than here in the U.S. What do these statistics tell us about how we should deliver health care in our country? Not very much. Mortality rates depend on many factors that often have little to do with the health care delivery system, such as the general health of the population and lifestyle choices such as smoking. Linking health care reform to breast cancer mortality is complex. We simply do not know how to quantify the connection. We do know that all women with and at risk of breast cancer deserve access to quality health care. The attached analysis explains the

complexity of the statistics and the reality of the connection between a health care system and breast cancer deaths.

There are three million women living with breast cancer in this country today. This year, more than 40,000 will die of the disease and more than 240,000 will be diagnosed. We still do not know how to prevent breast cancer, how to diagnose it truly early or how to cure it. It is an incredibly complex disease and we must be very careful that the actions we take are the right ones that will move us forward and will not result in harm to the women they are intended to help.

Conclusion

We believe we have made progress in breast cancer. Yet time and again we are reminded that we have made much too little.

NBCC lost a passionate, strong and brilliant advocate in June of this year to soft tissue sarcoma, a side effect of past breast cancer treatment. She died not from breast cancer, but from her treatment for breast cancer. Carolina Hinestrosa served as Executive Vice President at NBCC and was the co-founder Nueva Vida, a support network for Latinas with breast and cervical cancer. Nueva Vida formed in 1996, two years after Carolina was diagnosed with breast cancer at the age of 35. Carolina was born in Bogota, Colombia and came to the United States in 1985 as a Fulbright Scholar to pursue a master's degree in economic development. She worked as a business economist in Colombia and New Zealand before returning to Washington, DC in 1993. Carolina had incredible courage and compassion. She dedicated herself to pushing the research community to think about their work differently and to focus on saving lives. Her contributions to NBCC and to the breast cancer community were significant and will continue to live on as will her spirit through all of us who continue in this fight.

The individuals who comprise the myriad of organizations that make up NBCC have selflessly given of their time and of themselves and have made great sacrifices to work toward this cause. They do not continue this important work because they think it will benefit them. In fact, some of our advocates with metastatic breast who continue to fight and keep coming to Washington do so knowing full well they will never see the breakthroughs and progress in research and access to care. It is a sense of obligation and purpose on the part of these women to contribute toward something greater than themselves and the commitment and desire to help bring about a day when our daughters and granddaughters and great-granddaughters will not have to confront this disease.

Linda Croucher is NBCC Volunteer Lead Field Coordinator for Ohio and a member of the board of the Breast Cancer Alliance of Greater Cincinnati. These are her words:

“There are so many women, not only in Ohio, but all across the United States that depend on research as a hope for a cure for breast cancer. Unfortunately, with the extent of my disease, it is doubtful that I will ever be cured. Having said that, I do hope for a cure for my two girls, Sarah and Molly. I am the fourth generation in

my family to be diagnosed with breast cancer. I cannot bear to think about my daughters suffering the same fate.”

We owe all of these women, their families and friends, the strongest, most meaningful and exact policies to achieve our mission to end breast cancer. For now, let’s focus our efforts in breast cancer on making certain all women and their families, everyone in this country, has access to the quality care they need.

Mr. Chairman, I thank you so very much for this opportunity to testify before this Committee and for the Committee’s commitment to our mission.