

NBCC

NATIONAL BREAST CANCER COALITION

grassroots advocacy in action

**Testimony of
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**Submitted to the
House Education and Labor Committee**

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Thank you, Chairman Miller and members of the House Education and Labor Committee for the opportunity to testify at your hearing on the *Tri-Committee Draft Proposal for Health Reform*. I am honored to have this opportunity to appear before you today.

I am Fran Visco, a 21-year breast cancer survivor, a wife and mother, a lawyer, and President of the National Breast Cancer Coalition (NBCC). This organization and the testimony I present today represent the hundreds of member organizations and thousands of individual members from across the country.

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.

The National Breast Cancer Coalition Framework for Health Care Reform

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 Health 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 to coverage 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 health care. I am submitting a copy of the *NBCC Framework* for the record.

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 too few women have access to the care they need. We simply can no longer afford to accept the status quo when it comes to our health care system.

Our long standing commitment to health care reform is driven by the experiences and stories of the millions of women who have not only received the devastating diagnosis of breast cancer but have also had to suffer the injustices of our current health insurance system. We hear and live these stories, from women who share their breast cancer drugs with others who are un- or underinsured, to those who delay treatment or who ignore symptoms because they do not know how to pay for care. There are far too many stories.

Carolyn, from Los Angeles, had insurance and access to tamoxifen. So did one other woman in her breast cancer support group. But others lacked insurance and the funds to pay for treatment. So Carolyn and her friend shared their tamoxifen with these women. No one received the right amount of the drug.

Patricia from New Hampshire is 61, her husband 64. When he was laid off after 27 years, they lost their health insurance. Then she was diagnosed with breast cancer. She found insurance, for herself, at \$929 per month. Their joint income was \$40,000.

Sonia from Florida was also uninsured at the time of her breast cancer diagnosis. She managed to find fragmented care, and was refused further treatment at other institutions. She could not find insurance – even if she could afford it - because of her pre-existing condition.

Mary, from Waterloo, Iowa worked for a large corporation that changed health plans in the middle of her breast cancer treatment. Her doctors and hospital were no longer covered and she was forced to leave her doctors in the midst of a complex treatment regimen.

These are just some of the representative stories of what women face today in our existing health care system.

The House Tri-Committee Health Reform Discussion Draft

Mr. Chairman, on behalf of NBCC, I commend you as well as the Chairmen of the House Energy and Commerce and the House Ways and Means Committees for your leadership and hard work in putting together a health care reform proposal to provide quality affordable health care for all Americans and control health care costs. We are also pleased to see that your draft legislation includes many of the key elements that are reflected in NBCC's *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All (Framework)*.

NBCC's Framework calls for a health care system in which coverage is guaranteed to all individuals, does not discriminate or deny coverage for any reason, including pre-existing conditions. We are pleased that the draft legislation establishes options and expands Medicaid

eligibility. All of these elements are critical to ensuring that those with insurance they like can keep it while also giving those for whom insurance has been out of reach the opportunity to finally afford coverage for themselves and their family.

While the public plan option was not included in our original Framework, the NBCC Board of Directors recently endorsed this approach because it believes a public plan is important to providing patients' choice and injecting more competition into the insurance market, with the goal of keeping costs down.

We are pleased that the House Tri-Committee discussion draft bill guarantees coverage and ends many of the discriminatory insurance practices that have put meaningful coverage out of reach for many Americans with millions more in fear of losing their coverage should they experience a catastrophic illness such as breast cancer. Specifically, your bill prohibits pre-existing condition exclusions and also bars plans from rating based on gender or health status. The bill also includes several provisions to keep health care affordable, including no annual or lifetime limits on benefits as well as an annual cap on out of pocket spending and sliding scale credits based on income to help people afford to purchase insurance.

NBCC's Framework calls for an independent public/private Federal-level board to determine the benefits package. The basic benefits package should be equivalent to the most comprehensive plan available to members of Congress through the Federal Employees Health Benefit Plan (FEHBP) and should guarantee coverage for care that is based on scientific evidence and is continuously reviewed and updated based on evidence.

We are pleased that your legislation proposes a new 18-member public/private independent Federal-level *Health Benefits Advisory Committee (Committee)* that will recommend a new essential benefit package that will establish a core set of comprehensive benefits, make periodic updates to the benefits, and caps the amount of money a person or family spends on covered services in a year. We urge the Committee to ensure that the basic benefit package is as comprehensive and guarantees coverage for care that is based on the best available scientific evidence and is cost effective. It is imperative that the core set of benefits be available to everyone, regardless of ability to pay. Moreover, the benefits should be limited to those interventions determined to be efficacious, safe, cost-effective and based on sound evidence, or as part of a clinical trial or otherwise appropriately contributing to the evidence base.

NBCC strongly supports comparative effectiveness research and believes that it is necessary to help ensure quality, affordable health care 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 and 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 research of interventions in the real life settings all doctors and patients face. Comparative effectiveness research is a term to describe this second component. It provides an opportunity to conduct research 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.

Women – all individuals – should have access to care that helps them, care that improves their lives. Today there is increasing use of technology in health care, certainly in breast cancer, with increased cost and little known benefit to patients. Comparative effectiveness will help guide us through this maze. For example, it could tell us which of the many gene based tests on the market actually are accurate and clinically useful. Also, as we strive to detect breast cancer earlier and earlier, we tend to find many abnormalities that will never become life threatening, yet we do not know how to deal with this information. *Ductal carcinoma in situ* (DCIS) is one such condition. DCIS is treated like it is cancer, so we over treat many women with significant harmful side effects. Comparative effectiveness research can tell us which of the various interventions for DCIS are the most helpful and least harmful.

There is a breast cancer drug that has been hailed as a breakthrough. It is a targeted therapy that costs tens of thousands of dollars a year. There are at least two tests to determine which women will benefit from this drug and we have known for over a decade that one provides much more accurate information. Yet we still pay for both tests and for the drug in women who will not benefit. And many women who would benefit do not get the drug. There are many similar questions that we have known for years that women face every day. We do not have the answers, but we could.

This rational approach to health care can significantly improve care. However, for comparative effectiveness research to do so, it depends on the following:

- **Quality** – Comparative effectiveness research must be held to the highest standards of quality. This research must employ rigorous methods that can provide reliable answers to our specific questions. These may include experimental designs, observational studies like registries, systematic reviews and other methods. Incorporating new technologies to better understand the utility of biomarkers and the interplay of co-morbidities will help achieve the promises of biomedical research progress on an individual level. Great care needs to be taken to ensure that there are clear standards of quality so the investment in comparative effectiveness research delivers value to the public.
- **Transparency** – Doctors, patients and policy makers must be able to trust the results of comparative effectiveness research. While quality is vital to that goal, transparency and accountability are also key. The processes for setting priorities, defining criteria and reporting results must be transparent and easily accessible to all. Methods and data must be shared so they can be publicly critiqued and widely used in a practical manner. Moreover, trained lay consumer advocates must be meaningfully involved in all aspects of decision-making that affects comparative effectiveness research.
- **Independence** – Comparative effectiveness research infrastructure must be sheltered from political pressure. The usefulness and value of comparative effectiveness research lie in its independent assessment of different interventions, the results of which can be used by all the different stakeholders in decision-making. The process for selection of topics to be studied must be objective, and the results must be credible. The entire research process must be insulated from political pressures and conflicts of interest generated by both government and private-sector stakeholders.

- **Integrity** – Comparative effectiveness research must be conducted with integrity. High quality methods, accurate and detailed record keeping, and honest publication of the results, regardless of the outcome, must be emphasized. All contributors to comparative effectiveness research must publicly disclose all relevant relationships and conflicts of interest. Institutional guidelines and procedures must be in place to define and address conflicts.

Comparative effectiveness research must deliver value to the individual and society by strengthening the evidence base, enabling better decision-making, improving health outcomes, more fairly allocating healthcare resources, and containing the currently unsustainable health care costs.

We are pleased that your draft legislation builds upon the foundation that was set forth in the *American Recovery and Reinvestment Act of 2009 (ARRA)* to provide for a robust and rigorous comparative effectiveness research program. Specifically, your legislation creates a *Comparative Effectiveness Commission* that has been tasked with advising, overseeing and evaluating the research and findings of the *Center for Comparative Effectiveness Research* at the *Agency for Healthcare Research and Quality*. Your legislation seeks to ensure transparency, credibility, and access to research by requiring the disclosure of any conflicts; providing stakeholders input into the process; requiring the dissemination of the findings; and creating a *Comparative Effectiveness Research Trust Fund (CERTF)* to ensure that this critical research receives adequate funding and is not subject to an annual appropriations process. Such efforts are essential to ensuring that the public and providers are informed, and therefore patients receive, the most effective and appropriate treatment for their particular condition. Such research will greatly enhance the delivery of efficient, effective and high quality care that provides true benefit to patients in need. We simply cannot and should not continue to tolerate the massive amounts of wasteful, inefficient and in some cases, harmful care being administered in today's broken health care system.

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 evidenced-based treatment options, their cost effectiveness, decide the level of benefits and determine effective methods for communicating health care information to consumers, providers and plans. Patient advocates – members of the lay public who are educated and trained – can play an integral role in ensuring that the health care system is responsive to the needs of the medical and scientific communities as well as health care consumers. Their perspective is necessary to ensure that decisions regarding benefit packages, insurance reforms, research and other aspects of the health care system are meaningful and will have a positive impact for those on the receiving end of health care – the patients and their families. The perspective of patients and families is also important as they are the ones who must navigate the complex web of rules and requirements in any health insurance system.

The leadership and membership of the various committees and commissions contemplated by your bill will determine its success. These individuals, no matter which constituency they

represent, must be chosen based on their proven ability to participate in these types of decisions. We are pleased that your draft bill demonstrates your commitment to ensuring that patients, consumers and their families have a strong voice and role to play in a reformed health care system. In particular, we are heartened to see that the independent private-public *Health Benefits Advisory Committee* assigned to provide recommendations on a benefit package would include consumer representatives. We also appreciate that your bill provides patient advocates a role to play on the *Comparative Effectiveness Commission*. We would however encourage you to specify that 25 % of these committees are comprised of consumers or patient advocates to ensure that they can contribute to this process in a meaningful way. We also would ask that you consider integrating the following language everywhere such entities are described in your bill:

“The term ‘educated consumer or patient advocate’ means an individual who is accountable to, represents and reports back to organizations that represent those affected by a specific disease or medical condition and is knowledgeable about the health care system and has received training to make informed decisions regarding health, medical and scientific matters.”

NBCC’s Framework calls for the implementation of strategies to significantly reduce the administrative cost of the health care system, to simplify the current system, reduce duplication, inaccuracies, and inefficient record keeping and provide for system-wide electronic record keeping.

We are pleased that your discussion draft makes a priority of appropriately controlling the rising cost of health care. Your proposal will reduce the growth in health care spending in numerous ways including health care delivery system reform and improvements in payment accuracy. Your legislation will realign payment incentives to reduce overuse, slow the growth of health care costs, and improve Americans' health. Your bill will also ensure physician and patient access to the latest and most scientifically complete information on available medical treatments and will invest in development of robust quality measures on health outcomes.

NBCC’s Framework calls for shared responsibility. The system should be financed in part through cost savings and shared responsibility. Everyone – individuals, employers, and government – share responsibility to support the health care system. Individuals should be required to financially contribute to the system based on their ability to pay. All employers should be required to contribute to the system. Subsidies or a sliding scale should be implemented to ensure that small businesses are not disproportionately affected by these payments. And no individual can be denied coverage for inability to pay.

We are pleased that your plan provides sliding scale affordability credits to low and moderate income families and assistance to small employers.

We are pleased that your draft legislation recognizes that for health care reform to be successful and sustainable over the long-term, it will require the shared responsibility and commitment of all participants in the system – individuals, employers and the government.

Commitment of the National Breast Cancer Coalition

NBCC is strongly committed to achieving meaningful health care reform this year, as we truly believe it is essential for all women with or at risk for breast cancer and for everyone to have access to high quality, affordable and reliable health insurance coverage. Without it, advances in medical research will remain out of reach for many individuals and patients in need and we cannot guarantee those who have been diagnosed with breast cancer will receive the necessary treatment or medical care that is critical to their successful recovery. NBCC and its members are dedicated to working with you to achieve affordable quality health care for all.

Thank you again for the opportunity to testify today and for giving hope to all women and their families, and especially to the 3 million women in the United States living with breast cancer. I look forward to working with you to ensure that health care reform is enacted into law this year.

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NBCC's *Framework for a Health Care System* *Guaranteeing Access to Quality Health Care for All* April 2008

The National Breast Cancer Coalition (NBCC) has advocated for guaranteed access to quality health care for all since its inception in 1991. In 2003 NBCC adopted its *Principles for Achieving Guaranteed Access to Quality Health Care for All*. NBCC analyzed various approaches to achieving its goal in order to develop public policy that moves beyond incremental changes to the existing health care system toward true comprehensive reform. NBCC's extensive research and analysis gave rise to its *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All*. This *Framework* is intended primarily to address the issue of health care coverage. NBCC continues to work on approaches to quality and access beyond coverage.

NBCC presented the *Framework* at its Annual Advocacy Training Conference in April 2008 and NBCC advocates presented it to their Members of Congress during Lobby Day on April 29th. NBCC looks forward to working with Members of Congress and other stakeholders to advance the goals articulated in the *Framework*.

Key Points of NBCC's Framework

- The *Framework* is premised on the fundamental belief that health care is a right and that all people present in the United States should have access to quality health care regardless of their immigration, residency status, or ability to pay.
- The *Framework* is an outline for legislation that will support a system of evidence-based health care coverage for everyone.
- The *Framework* provides that the basic benefits covered are comprehensive and evidence-based.
- The system resulting from the *Framework* will include mechanisms to:
 - Support development of new evidence through clinical research
 - Continually refine benefits through comparative effectiveness and cost effectiveness analyses
 - Reduce over and under use of care
 - Include educated consumers in all decision making
- The system will be financed in part through cost savings and shared responsibility:
 - Everyone – individuals, employers, and government – share responsibility to support the system.

- Individuals will be required to financially contribute to the system based on their ability to pay.
- All employers will be required to contribute to the system. The *Framework* would phase out employer-sponsored health insurance. Subsidies or a sliding scale should be implemented to ensure that small businesses are not disproportionately affected by these payments.

The National Breast Cancer Coalition's number one public policy priority is guaranteed access to quality health care for all. This document outlines a *Framework* developed by NBCC's Board of Directors that is based on the organization's Principles for Guaranteed Access to Quality Health Care for All adopted in 2003. This *Framework* addresses a legislative approach to coverage issues. NBCC recognizes that access to quality health care goes beyond coverage. A health care system that is built on this *Framework* will:

- provide a basic benefits package that is comprehensive and based on sound scientific evidence;
- maintain continuity of coverage;
- be efficient and cost-effective;
- be fully-funded through shared financial responsibility;
- be sustainable and affordable.

The health care system must be accountable to the users and the public. A system must be established to:

- evaluate and support development of medical evidence for health interventions upon which coverage will be based;
- support ongoing and continuous comparison of interventions to ensure access to appropriate and cost-effective health care;
- modify and expand current benefits as appropriate based on evidence.

I. Benefits Package

1) All eligible individuals will be provided with coverage for a benefits package equivalent to the most comprehensive plan available to Members of Congress through the Federal Employees Health Benefit Plan.

2) The benefits package guarantees coverage for care that is based on the best available scientific evidence and is cost effective (as determined by the Federal board described below). Care that does not meet these criteria will not be covered, unless it is being provided as part of a quality clinical trial or otherwise appropriately contributing to the further development of the evidence base.

II. Eligibility

1) Coverage is guaranteed to all eligible individuals.

- a) An eligible individual is one who is present in the United States. (Note: the extent of coverage will vary based upon reason for presence and duration of stay).
- 2) All eligible individuals will be automatically enrolled and covered at the point of attaining eligibility.

III. Determination of, Modifications to and Expansion of Benefits:

1) A Federal-level board shall have the authority to implement a system of coverage determination based on evidence. The board shall be appointed and include members representing the lay public (at least 25%). The members shall have staggered terms longer than 4 years.

- a) Cost-effectiveness shall be a factor considered by the Board in making benefit coverage decisions.

2) A separate and independent body, including at least 25% membership from the lay public, shall be appointed to develop a system for assessing comparative effectiveness of interventions, the results of which must be utilized by the board determining coverage benefits.

3) The comprehensive benefits package and any modifications thereto shall be limited to those interventions that the boards deem to be: efficacious, safe, cost-effective, based on sound evidence; or either as part of a quality clinical trial or otherwise appropriately contributing to the evidence base.

4) Elective Benefits

- a) Commercially available private health plans may provide coverage of benefits not included in the benefit package.

IV. Efficiency

1) The government shall implement strategies to significantly reduce the current administrative costs of the health care system and all such savings shall go toward providing coverage.

2) The government shall also develop and implement strategies to simplify the current system, reduce duplication, inaccuracies, and inefficient record keeping and provide for system-wide, interoperable electronic record keeping.

V. Information and Education

1) Accurate, timely, and readily accessible information about health care coverage, access and the scientific evidence base shall be available to everyone. All health care providers

must offer clear information to consumers on the benefits and harms of all options, and the quality of the evidence for each option.

2) A national panel shall be established to work with the public to review evidence and help design effective methods for communicating health care information to consumers, providers and plans.

VI. Financing

1) All individuals are required to financially contribute to the system according to their ability to pay.

2) All employers are also required to financially contribute to the system. Under this *Framework* employer-sponsored health insurance will be phased out, however, all employers are required to financially contribute to the system.

3) The federal government shall establish a method for determining the financial contributions for individuals and employers.

4) No individual can be denied coverage because of inability to pay.

5) In addition to individual and employer contributions, the system will be financed by the public and private savings from efficiencies (referred to in the section on efficiency) as well as other government funding sources.