

Susan G. Komen Breast Cancer Bill of Rights Background

<u>1. ACCESS: Breast cancer patients and survivors have a right to continuous, affordable, guality and accessible health insurance coverage</u>.

Every woman should have the right to access continuous, affordable and guaranteed health coverage regardless of pre-existing conditions or current circumstances. We must ensure affordable cost sharing for all vital treatments and chemotherapy options.

<u>2. CLINICAL TRIALS: Breast cancer patients should be educated about clinical trial</u> opportunities and patients who participate in a clinical trial have a right to coverage of routine health care costs.

Eligible patients should be afforded the opportunity to participate in a clinical trial without fearing an insurance company might drop them from coverage or limit their coverage. Patients and their doctors should be made aware of active clinical trials.

<u>3. EARLY DETECTION: Every woman has a right to access the most effective, evidence-</u> based breast cancer screening and diagnostic tools that may save her life.

Screening mammography is currently covered as a preventive service under most insurance plans, however, should the preventive services be eliminated or altered, many women will not have the ability to cover the out-of-pocket costs for a mammogram. Additionally, many women, currently, are still not able to afford necessary follow-up diagnostics. We must ensure every woman is able to access necessary screenings and diagnostic services without the fear of having to pay a high deductible or copay.

4. FINANCIAL STABILITY: Women who are diagnosed with breast cancer have a right to fight the disease without fear of bankruptcy.

Cancer treatments can be very expensive and require long-term monitoring and follow-up care, potentially exposing patients to significant financial hardship. We must ensure current financial protections remain intact, and that patients who may have recently lost their coverage are not faced with new financial burdens to regain health coverage.

5. HIGH QUALITY: Every woman has a right to high-quality care, no matter where she seeks medical services.

Breast cancer screening, diagnostic, treatment and follow-up care decisions should be made between a woman and her doctor based on the latest technology and guidelines developed by professional organizations like the National Comprehensive Cancer Network or the American Society of Clinical Oncologists.

<u>6. INNOVATION: All Americans have a right to a government that makes investment in cancer research a national priority.</u>

It is vital that federal and state governments prioritize cancer research and infrastructure. As our understanding of breast cancer continues to evolve, we need to develop technologies and screening approaches that are more specific, more personalized and more accurate — and we

need to deliver them to patients as safely and quickly as possible. It is critical that recent investments in cancer research and personalized medicine are not forgotten or diminished.

7. PATIENT EDUCATION: Every woman has a right to make informed decisions and control her own health.

Every woman diagnosed with breast cancer deserves the best care possible. The Institute of Medicine says good quality care is "providing patients with appropriate services in a technically competent manner, with good communication, shared decision-making and cultural sensitivity." Women should understand their rights and their personal risk of breast cancer — as well as their screening, diagnosis and treatment options, and the risks and benefits of each option. Additionally, as part of informed decision-making, patients should have a right to a second opinion. Additionally, we must continue to educate young women and their providers about breast cancer in young women.

8. <u>RECONSTRUCTION</u>: Breast cancer survivors have a right to insurance coverage for full mastectomy care, including reconstruction or prosthesis.

Every woman has the right to be fully aware of their options to make informed health care decisions. All breast cancer survivors with health insurance have a right to coverage, payment or reimbursement for full mastectomy care including reconstruction, thanks to the *Women's Health and Cancer Rights Act of 1998.* Women not covered by health insurance should have the same opportunities to make informed healthcare decisions.

<u>9. STRONG SAFETY NET: Uninsured and underinsured women have a right to a strong</u> breast health care safety net.

We must ensure a strong safety net is accessible for women who have been unable to gain health insurance coverage, or might lose health insurance coverage due to changes in the current health care system. Underserved women have access to breast cancer screening through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), a joint program run by the Centers for Disease Control and Prevention (CDC) and the states. A woman diagnosed through NBCCEDP has a right to Medicaid coverage for her breast cancer treatment. Unfortunately, NBCCEDP is chronically underfunded — only one in five eligible women have access.

<u>10. TIMELY CARE: Every woman who has an abnormal mammogram has a right to a diagnosis and treatment, if needed, without delay.</u>

We must break down institutional barriers that delay access to timely diagnosis and treatment; however, it is also important that every woman has the time to make educated, well-informed decisions about her treatment.