



## 2024 Legislative and Public Policy Priorities

### Legislative Priorities

#### PRIORITY #1:

**\$150 Million/Level Funding for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for FY2025:** As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 to end breast cancer for Service Members, Veterans, and the general public by funding innovative, high-impact research through a partnership of scientists and consumers. The DOD BCRP is widely viewed as an innovative, unique, and efficient medical research model which has proven to be accountable to the public and has produced extraordinary results. NBCC seeks continued level funding.

#### PRIORITY #2:

**Metastatic Breast Cancer Access to Care Act (H.R. 549/S.663)** This legislation would waive the 24-month waiting period for Medicare and the five-month waiting period for Social Security Disability Insurance benefits for eligible individuals with Metastatic Breast Cancer.

#### PRIORITY #3:

**Preservation of the Medicaid Breast and Cervical Cancer Treatment Program:** Congress enacted the Breast and Cervical Cancer Treatment Act in 2000 after years of NBCC grassroots lobbying and influence. NBCC remains committed to ensuring all women and men screened and diagnosed with breast cancer have access to the treatment they need.

### Public Policy Priorities

#### PRIORITY #1:

**Guaranteed Access to Quality Care for All:** Ensuring access to quality evidence-based health care has been a top priority of NBCC for many years. NBCC supports healthcare access initiatives that expand access to Medicare while offering a private insurance option, automatically enrolling individuals who do not have access to other coverage and providing guaranteed benefits, including primary and preventive care, hospital services, and prescription drug coverage. NBCC believes that there must be shared financial responsibility and that no individual should be denied coverage due to an inability to pay.

#### PRIORITY #2:

**Access to Affordable and Effective Therapies:** NBCC supports policies that address systemic deficiencies in the law, regulation, and science policy that result in the approval of drugs that do not significantly extend or save lives and whose prices are not based on value or effectiveness.

#### PRIORITY #3:

**Food & Drug Administration (FDA) Reform:** NBCC supports a drug approval system that prioritizes approving drugs with clinically meaningful benefits for patients. NBCC seeks to address systemic deficiencies in FDA regulation and



the drug development process, including reforms to the accelerated approval pathway and the use of unvalidated surrogate endpoints.

#### PRIORITY #4:

**Ensure the Participation of Educated Patient Advocates in Science Research and All Levels of Health Care Decision Making:** NBCC continues to work to ensure that educated patient advocates who are trained and represent a constituency have a meaningful seat at the table in all levels of health care decision-making, which affects their lives.



## \$150 million for the Department of Defense (DOD) Peer-Reviewed Breast Cancer Research Program (BCRP) for FY2025

### Background

The DOD BCRP was created in 1992 as a result of the National Breast Cancer Coalition's "\$300 Million More" campaign to increase federal funding for breast cancer research. Due to NBCC's efforts and the Congressional leadership of Senators Tom Harkin (D-IA) and Alfonse D'Amato (R-NY) in FY1993, Congress appropriated \$210 million in the DOD research and development budget for a breast cancer peer-reviewed research program administered by the Department of the Army. As a result of NBCC's grassroots advocacy and the DOD BCRP's demonstrated success, Congress has appropriated funding for it each year since.

### A Model Medical Research Program

Since its inception, the DOD BCRP has sought to "eradicate breast cancer by funding innovative, high-impact research through a partnership of scientists and consumers." It has grown from a small research program to a far-reaching, influential model that others have sought to replicate throughout the cancer and broader medical research community. Some of the keys to the DOD BCRP's success are:

- It is innovative and unique. The DOD BCRP has a unique grant structure that allows it to be more flexible than other traditional competitive, peer-reviewed medical research programs. This structure can fund innovative, high-risk, high-return research and quickly respond to current scientific advances. The DOD BCRP can also fill gaps by focusing on promising but otherwise underfunded research areas. In its reviews of the DOD BCRP, the Institute of Medicine has stated, "the program fills a unique niche among public and private funding sources for cancer research. It is not duplicative of other programs and is a good vehicle for forging new ideas and scientific breakthroughs in the nation's fight against breast cancer."
- It is efficient. Due to the program's flexibility, the Army can administer it with unparalleled efficiency and little bureaucracy. The program allows approximately 90% of the appropriated funding to go directly to competitive, peer-reviewed research grants awarded to the best science.
- It is accountable to the public and transparent. Information on all funded grants is posted on the program website, accessible to the public. In addition, educated, trained consumer advocates participate in a two-tiered process where research proposals are reviewed for scientific quality and programmatic relevance. This consumer involvement allows grant funding decisions to be informed by trained breast cancer survivors and based on patient and medical communities' concerns and needs. It provides for those who have no agenda other than to end breast cancer for everyone. This transparency allows scientists, consumers, and the public to view the progress made in breast cancer research through the DOD BCRP.



- It has produced extraordinary results. From new methods of extracting breast cancer cells at their earliest stages, to unprecedented research into gene/environment interaction, to quality-of-life issues, the DOD BCRP leads the way in generating new approaches to breast cancer prevention and treatment. It has produced fascinating insights into the biology of breast cancer. It has directly impacted lives through the research it has funded, such as the revolutionary work that led to the development of the innovative drug Herceptin.

The DOD BCRP owes its success to the integrated efforts of its partners – from the ongoing dedication of the U.S. Army and their belief and support of this mission to the Members of Congress who support the program through continued funding to the scientists and consumers who participate, and to the researchers who every year submit proposals that reach the highest level asked of them by the program.



## Metastatic Breast Cancer Access to Care Act, 118<sup>th</sup> Congress (H.R. 549, S. 663)

Legislation to waive the 24-month waiting period for Medicare and the 5-month waiting period for Social Security Disability Insurance benefits for eligible individuals with metastatic breast cancer.

### Background

Metastatic breast cancer is cancer that has spread from the breast to the bones, lungs, or other distant parts of the body. Unfortunately, 90% of breast cancer deaths are a result of metastatic disease. There are treatments, some of which have extended survival for women and men with metastatic breast cancer, but today, there is no cure.

Individuals diagnosed with metastatic breast cancer automatically qualify for disability benefits from the Social Security Administration (SSA) and for Medicare coverage regardless of age, as long as they apply and meet the SSA's technical qualification rules. An individual must have been employed within the last ten years and currently unable to work due to her or his disability to earn Social Security disability insurance benefits (SSDI). Once an individual is approved for SSDI, there is a five-month waiting period to begin receiving benefits and a twenty-four-month waiting period for Medicare coverage.

### Federal Precedent for Extended Coverage

Applying waiting periods to individuals with a lethal disease like metastatic breast cancer is arbitrary and cruel. The National Breast Cancer Coalition urges Congress to enact legislation to amend the Social Security Act to eliminate waiting periods for disability insurance benefits and Medicare coverage for eligible individuals with metastatic breast cancer.

In 2001, Congress passed a bill to add Amyotrophic Lateral Sclerosis (ALS) as a qualifying condition for automatic Medicare coverage and, in 2020, waived the five-month waiting period for SSDI for individuals with ALS, thus creating a federal precedent. Based on the limited life expectancy of individuals with metastatic disease, an average of 3 years, NBCC believes that both automatic SSDI and Medicare coverage should also apply to metastatic breast cancer patients who qualify.

### Action Requested

NBCC urges Congress to enact legislation which would amend the Social Security Act to waive all waiting periods for Medicare and Social Security Disability Insurance for eligible individuals with metastatic breast cancer.



## Prescription Drug Pricing Should be Based on Value

### Background

The National Breast Cancer Coalition's mission is to end breast cancer. We cannot achieve that mission until all individuals with and at risk of breast cancer have access to the quality health care they need. Access requires a system that facilitates affordable and effective treatments. One step to achieve that goal is to make certain that breast cancer drug pricing is based on value.

The cost of breast cancer care continues to rise. Overall, the national cost of cancer care in 2015 was \$183 billion, with a minimum projected increase of 34 percent to \$246 billion by 2030 based solely on the aging and growth of the U.S. population<sup>1</sup>. On top of that are anticipated increases in national costs for medical services and prescription drugs, which are predicted to increase during this period by 34 percent and 40 percent, respectively.

Patients make critical contributions to the discovery of new drugs through their participation in clinical trials and lobbying for research funding, in addition to paying taxes to support federally funded research.

Federal agencies spent \$243 billion in taxpayer dollars in 2018 on medical and health research and development, much of it on competitive grants given for early-stage research. Findings from federally funded research are the basis for the product development work done by private pharmaceutical companies. U.S. tax dollars, allocated through NIH grants, were used to discover every pharmaceutical product approved by the FDA from 2000 to 2016.<sup>2</sup> In addition to funding scientific findings via grants, the federal government encourages drug development by providing tax incentives. Drugmakers may write off some of the amount they spend each year on research and development using one or a combination of tax incentives.

Patients are then rewarded with drugs that create both financial and health toxicities. And despite the increasing cost of prescription drugs, most approved breast cancer drugs have not been shown to extend life.

The national goal should be to bring about drugs that save lives. Yet the priorities in the existing system are to protect proprietary interests and maximize profits. For example, patent laws were created to incent discovery and reward inventors but today's patent system benefits institutions and industry at the expense of patients and the healthcare system.

Countries such as Britain and Germany have taken extensive steps to introduce cost-effectiveness assessments into their healthcare systems, refusing to pay higher prices for new drugs that do not improve treatment effectiveness over existing



options.

NBCC urges Congress and the Administration to support initiatives that address systemic deficiencies in law, regulation, and science policy that result in the approval of drugs that do not significantly extend or save lives and whose prices are not based on value or effectiveness.