NBCC

NATIONAL BREAST CANCER COALITION

2021 Legislative and Public Policy Priorities

Legislative Priorities

PRIORITY#1:

$150 Million for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for FY2022: As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 to eradicate breast cancer 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 Accessto Care Act (S. 1312/H.R. 3183): A bill to 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. This legislation would waive all waiting periods for Medicare and SocialSecurity Disability Insurance (SSDI) benefits based on disability for 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 health care access initiatives that expand access to Medicare while also offering a private insurance option, automatically enroll individuals who do not have access to other coverage, and provide 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:

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 represent a constituency have a meaningful seat at the table in all levels of health care decision making, which affects their lives.

Patient advocates must:

- Have a patient-led, patient-centered organization with a patient constituency to which they are responsible and accountable;
- Have been personally affected by disease; and
- Be knowledgeable, trained, prepared and confident in their ability to participate in the decision-making process of science and medicine.

Legislative Priority #1: $150 million for the Department of Defense (DOD) Peer-ReviewedBreast Cancer Research Program (BCRP) for FY 2022

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 "accelerate high-impact research with clinical relevance, encourage innovation and stimulate creativity, and facilitate productive collaborations." It has grown from a small research program to a far-reaching, influential model that others throughout the cancer and broader medical research community have sought to replicate. 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 areas of research. 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 both the 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 developing the innovative drug Herceptin.

The DOD BCRP also 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.

April 28, 2021

The Honorable Betty McCollum
Chair
Committee on Appropriations
Subcommittee on Defense
H-405, The Capitol
Washington, DC 20515

The Honorable Ken Calvert
Ranking Member
Committee on Appropriations
Subcommittee on Defense
1036 Longworth HOB
Washington, DC 20515

Dear Chairwoman McCollum and Ranking Member Calvert:

In 2021, it is estimated that 281,550 new cases of invasive breast cancer were diagnosed among U.S. women, approximately 2,650 new cases among U.S. men, and more than 44,000 individuals will die of the disease this year. In addition to invasive cancers, 49,290 new cases of in situ breast cancer will be diagnosed among women in the U.S. in 2021. While we have made some progress in prevention efforts, more accurate diagnosis, and better treatments, much work remains to be done to end breast cancer once and for all. As a nation, we must continue to show a commitment to changing these statistics.

Fortunately, thanks to your leadership and support, as well as that of the Department of Defense (DOD) Appropriations Subcommittee and the entire Appropriations Committee, the DOD peer-reviewed Breast Cancer Research Program (BCRP) has led the way in the fight against breast cancer since it began in 1992. Now, the DOD BCRP offers true promise in finding the answers necessary to end breast cancer for good. **In order to continue its progress towards this goal, we urge you to include robust funding for the DOD BCRP in the Department of Defense Appropriations bill for fiscal year (FY) 2022.**

As you both are aware, the DOD BCRP has established itself across the nation and around the world as a model medical research program. Some of the keys to the DOD peer reviewed BCRP's success are:

- **It is innovative and unique.** The DOD BCRP has a unique grants structure that allows it to be more flexible than other traditional competitive, peer-reviewed medical research programs. Due to this structure, it is able to fund innovative, high-risk, high-return research and quickly respond to current scientific advances. In addition, the DOD peer-reviewed BCRP can fill gaps by focusing on areas of research that are promising but otherwise underfunded. 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 promising vehicle for forging new ideas and scientific breakthroughs in the nation's fight against breast cancer."
- **It addresses specific needs.** The DOD BCRP directs research to address specific health concerns that are a priority and identifies the specific research areas where funding is to be allocated.

- **It is efficient.** Approximately 90 percent of the appropriated funding goes directly to competitive, peer-reviewed research grants awarded to the best science.
- **It is accountable to the public and transparent.** Educated, trained consumer advocates participate in a two-tiered process where research proposals are reviewed first for scientific quality, and then for programmatic relevance. This consumer involvement allows for grant funding decisions to be based on the real-life experiences, concerns, and needs of both the patient and medical communities. Once funded by the DOD BCRP, each researcher must present their results online on the program's website and at public meetings called "Era of Hope." 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.** The DOD BCRP has made significant scientific breakthroughs that have contributed to our understanding and treatment of breast cancer. For example, the drug trastuzumab (Herceptin) – developed as a result of research funded through the DOD BCRP – is prolonging the lives of women with a particularly aggressive type of advanced breast cancer that was previously untreatable.
- **It benefits all.** As the first of the Congressionally Directed Medical Research Programs (CDMRPs), the DOD BCRP strives to uphold the vision of the CDMRPs "to find and fund the best research to eradicate diseases and support the war fighter for the benefit of the American public." It does so by directly supporting the over 400,000 women currently serving on active duty and in the Reserves and National Guard, their male counterparts, and their families, as well as the millions living with breast cancer across the nation and around the world.

The DOD BCRP has proven itself a powerful weapon in the fight against breast cancer and continues to bring us closer to finding the answers necessary to end breast cancer once and for all. On behalf of the millions of Americans living with breast cancer, their families, and friends, **we ask you to continue your support for and investment in the DOD peer-reviewed BCRP and include robust funding in the Department of Defense Appropriations bill for FY2022.**

Sincerely,

Andrew R. Garbarino
Member of Congress

James P. McGovern
Member of Congress

Vern Buchanan
Member of Congress

Mikie Sherrill
Member of Congress

/s/
Alma S. Adams, Ph.D.
Member of Congress

/s/
Colin Allred
Member of Congress

/s/
Jake Auchincloss
Member of Congress

/s/
Cindy Axne
Member of Congress

/s/
Nanette Diaz Barragán
Member of Congress

/s/
Karen Bass
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Joyce Beatty
Member of Congress

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Ami Bera, M.D.
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Jack Bergman
Member of Congress

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Donald S. Beyer Jr.
Member of Congress

/s/
Sanford D. Bishop, Jr.
Member of Congress

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Earl Blumenauer
Member of Congress

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Lisa Blunt Rochester
Member of Congress

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Suzanne Bonamici
Member of Congress

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Mike Bost
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Brendan F. Boyle
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Anthony G. Brown
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Julia Brownley
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G. K. Butterfield
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Salud Carbajal
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Tony Cárdenas
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André Carson
Member of Congress

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Earl L. “Buddy” Carter
Member of Congress

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Sean Casten
Member of Congress

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Steve Cohen
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Gerald E. Connolly
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J. Luis Correa
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Jim Costa
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Joe Courtney
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Angie Craig
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Sharice L. Davids
Member of Congress

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Danny K. Davis
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Madeleine Dean
Member of Congress

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Peter A. DeFazio
Member of Congress

/s/
Antonio Delgado
Member of Congress

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Val Butler Demings
Member of Congress

/s/
Mark DeSaulnier
Member of Congress

/s/
Ted Deutch
Member of Congress

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Debbie Dingell
Member of Congress

/s/
Lloyd Doggett
Member of Congress

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Neal P. Dunn, M.D.
Member of Congress

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Anna Eshoo
Member of Congress

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Dwight Evans
Member of Congress

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Randy Feenstra
Member of Congress

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Brian Fitzpatrick
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Lizzie Fletcher
Member of Congress

/s/
Bill Foster
Member of Congress

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Ruben Gallego
Member of Congress

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John Garamendi
Member of Congress

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Jesús G. "Chuy" García
Member of Congress

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Jared Golden
Member of Congress

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Jimmy Gomez
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Vicente Gonzalez
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Jenniffer González-Colón
Member of Congress

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Bob Good
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Josh Gottheimer
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Garret Graves
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Raúl M. Grijalva
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Jim Hagedorn
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Jahana Hayes
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Brian Higgins
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Jared Huffman
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Sheila Jackson Lee
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Sara Jacobs
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Pramila Jayapal
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Hakeem Jeffries
Member of Congress

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Henry C. “Hank” Johnson, Jr.
Member of Congress

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Mondaire Jones
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John Katko
Member of Congress

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William R. Keating
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Ro Khanna
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Daniel T. Kildee
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Young Kim
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Andy Kim
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Ron Kind
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Ann McLane Kuster
Member of Congress

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Darin LaHood
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Rick Larsen
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Nicole Malliotakis
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Carolyn B. Maloney
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Sean Patrick Maloney
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Kathy Manning
Member of Congress

/s/
Doris Matsui
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Lucy McBath
Member of Congress

/s/
A. Donald McEachin
Member of Congress

/s/
Jerry McNerney
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Gregory W. Meeks
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Dan Meuser
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Mariannette Miller-Meeks
Member of Congress

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Gwen Moore
Member of Congress

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Joseph D. Morelle
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Seth Moulton
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Jerrold Nadler
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Grace F. Napolitano
Member of Congress

/s/
Richard E. Neal
Member of Congress

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Joe Neguse
Member of Congress

/s/
Ralph Norman
Member of Congress

/s/
Eleanor Holmes Norton
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/s/
Alexandria Ocasio-Cortez
Member of Congress

/s/
Ilhan Omar
Member of Congress

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Burgess Owens
Member of Congress

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Jimmy Panetta
Member of Congress

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Chris Pappas
Member of Congress

/s/
Bill Pascrell, Jr.
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/s/
Donald M. Payne, Jr.
Member of Congress

/s/
Scott Peters
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Dean Phillips
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Chellie Pingree
Member of Congress

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Stacey E. Plaskett
Member of Congress

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Katie Porter
Member of Congress

/s/
Bill Posey
Member of Congress

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Ayanna Pressley
Member of Congress

/s/
Daniel Black
Member of Congress

/s/
Jamie Raskin
Member of Congress

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Kathleen M. Rice
Member of Congress

/s/
Lucille Roybal-Allard
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/s/
Raul Ruiz, M.D.
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Bobby L. Rush
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Gregorio Kilili Camacho Sablan
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Michael F.Q. San Nicolas
Member of Congress

/s/
Linda T. Sánchez
Member of Congress

/s/
Mary Gay Scanlon
Member of Congress

/s/
Jan Schakowsky
Member of Congress

/s/
Adam Schiff
Member of Congress

/s/
Bradley S. Schneider
Member of Congress

/s/
David Scott
Member of Congress

/s/
Robert C. “Bobby” Scott
Member of Congress

/s/
Terri A. Sewell
Member of Congress

/s/
Brad Sherman
Member of Congress

/s/
Albio Sires
Member of Congress

/s/
Elissa Slotkin
Member of Congress

/s/
Christopher H. Smith
Member of Congress

/s/
Lloyd Smucker
Member of Congress

/s/
Darren Soto
Member of Congress

/s/
Abigail D. Spanberger
Member of Congress

/s/
Jackie Speier
Member of Congress

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Pete Stauber
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/s/
Haley Stevens
Member of Congress

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Marilyn Strickland
Member of Congress

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Thomas R. Suozzi
Member of Congress

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Eric Swalwell
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Mark Takano
Member of Congress

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Glenn 'GT' Thompson
Member of Congress

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Mike Thompson
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Paul Tonko
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Lori Trahan
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Jeff Van Drew
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Juan Vargas
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Marc Veasey
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Filemon Vela
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Nydia M. Velázquez
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Ann Wagner
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Michael Waltz
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Maxine Waters
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Peter Welch
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/s/
Susan Wild
Member of Congress

/s/
Nikema Williams
Member of Congress

/s/
Roger Williams
Member of Congress

/s/
Joe Wilson
Member of Congress

/s/
John Yarmuth
Member of Congress

/s/
Don Young
Member of Congress

/s/
Lee Zeldin
Member of Congress

/s/

Marie Newman
Member of Congress

Legislative Priority #2: Metastatic Breast Cancer Access to Care Act (S. 1312/H.R. 3183): Passage of legislation to waive the 24-month waiting period for Medicare and the 5-month waiting period for Social Security Disability Insurance benefits for eligible individualswith metastatic breast cancer.

Background

Individuals diagnosed with metastatic breast cancer automatically qualify for disability benefits from the Social Security Administration (SSA) 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 be unable to work due to her or his disability in order 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. Following approval of SSDI, individuals with metastatic breast cancer are eligible for Medicare coverage based on their disability. There is also a waiting period for Medicare coverage, once someone is deemed eligible

Eligibility for Medicare includes individuals over the age of 65, those with disabilities, and those with two specific diseases, End-Stage Renal Disease or Amyotrophic Lateral Sclerosis (ALS). Individuals under age 65 with disabilities other than ESRD or ALS must have received Social Security Disability Insurance (SSDI) benefits for 24 months before gaining Medicare eligibility. These eligibility rules include individuals diagnosed with metastatic breast cancer.

Metastatic breast cancer is cancer that has spread from the breast to the bones, lungs or other distant parts of the body. 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. There is no cure.

Federal Precedent for Extended Coverage

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 (H.R. 3183/S. 1312) which would waive all waiting periods for Medicare and Social Security Disability Insurance for individuals with metastatic breast cancer, and provide Medicare coverage including drugs and biologicals and all interventions used for the treatment and alleviation of symptoms relating to metastatic breast cancer.

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www.stopbreastcancer.org

[116H2178]

....
(Original Signature of Member)

117TH CONGRESS
1ST SESSION

H. R. ▌▌

To amend title II of the Social Security Act to eliminate the waiting periods for disability insurance benefits and Medicare coverage for individuals with metastatic breast cancer, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Ms. CASTOR of Florida introduced the following bill; which was referred to the Committee on ▌▌▌▌▌▌▌▌▌▌▌▌▌▌

A BILL

To amend title II of the Social Security Act to eliminate the waiting periods for disability insurance benefits and Medicare coverage for individuals with metastatic breast cancer, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the ''Metastatic Breast Can-
5 cer Access to Care Act''.

1 **SEC. 2. ELIMINATION OF WAITING PERIOD FOR INDIVID-**
2 **UALS WITH METASTATIC BREAST CANCER.**

3 (a) IN GENERAL.—Section 223(a) of the Social Secu-
4 rity Act (42 U.S.C. 423(a)) is amended—
5 (1) in paragraph (1), in the matter following
6 subparagraph (E), by inserting "or metastatic
7 breast cancer" after "amyotrophic lateral sclerosis";
8 and
9 (2) in paragraph (2)(B), by inserting "or (iii)"
10 after "clause (ii)".
11 (b) EFFECTIVE DATE.—The amendments made by
12 this section shall apply with respect to applications for dis-
13 ability insurance benefits filed after the date of the enact-
14 ment of this Act.

15 **SEC. 3. WAIVER OF 24-MONTH WAITING PERIOD FOR MEDI-**
16 **CARE COVERAGE OF INDIVIDUALS WITH**
17 **METASTATIC BREAST CANCER.**

18 (a) IN GENERAL.—Section 226(h) of the Social Secu-
19 rity Act (42 U.S.C. 426(h)) is amended by inserting "or
20 metastatic breast cancer" after "amyotrophic lateral scle-
21 rosis (ALS)".
22 (b) EFFECTIVE DATE.—The amendments made by
23 this section shall apply to benefits for months beginning
24 after the date of the enactment of this Ac

Legislative Priority #3: Preservation of the Medicaid Breast and Cervical Cancer Treatment Program

Background

After years of NBCC grassroots lobbying and influence, Congress enacted the Breast and Cervical Cancer Treatment Act (P.L. 106-354) in 2000. This law expanded access to health care for thousands of underserved women. The Act authorized enhanced matching funds to states to provide Medicaid coverage to uninsured or underinsured women diagnosed with breast or cervical cancer through a federal screening program. All 50 states, the District of Columbia, 5 U.S. territories, and 12 American Indian/Alaska Native tribal organizations opted into the Breast and Cervical Cancer Treatment Program (BCCTP). NBCC remains vigilant in ensuring that the program endures, and that eligible women continue to receive the lifesaving screening and treatment they deserve.

Importance of Maintaining the BCCTP

Before the BCCTP, women diagnosed through the federal Centers for Disease Control and Prevention (CDC) screening program—ineligible for Medicaid coverage yet unable to afford insurance on their own—were falling through the cracks. Following diagnosis, the legacy system left them to rely on an unreliable system of dwindling charity care. NBCC recognized this system's injustice and continues to believe that a federally funded program to screen and diagnose women with breast cancer must include a treatment component.

Since 1991, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) funded programs served more than 5.8 million women. The program provided more than 15.1 million breast and cervical cancer screening examinations and diagnosed 71,107 invasive breast cancers and 4,863 cervical cancers.

In May 2009, GAO published a report looking at the status of the Breast and Cervical Cancer Treatment Act entitled, "Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States." The report identified the screening source requirements as a barrier to women's eligibility for treatment in some states. A follow-up report was published in October 2020, "Federal Programs Provide Screening and Treatment for Breast and Cervical Cancer." GAO analysis of CDC data showed that as a result of Medicaid expansions enacted though the Affordable Care Act, some low-income women had additional resources for screening and treatment beyond the NBCCEDP, accounting for the

reduction in the number of women screened through the program from 2011 through 2017. There were additional barriers listed in the 2020 report like the 2009 report including certain requirements to qualify for the program.

Under the BCCTP, states must extend Medicaid eligibility to women or men whose screening or diagnostic services were paid specifically with CDC funds. States can be more generous in expanding Medicaid coverage under the BCCTP but cannot fall below this minimum standard.

While implementing health care reform through the Affordable Care Act increased access to breast and cervical cancer screening for low-income, underserved women, efforts to cut expanded insurance coverage and eliminate cost-sharing threaten their access to screening and treatment. Even with adequate health insurance, many women will still face significant obstacles to obtaining breast and cervical cancer screening and treatment due to geographic isolation, limited health literacy or self-efficacy, inconvenient times to access services, and language barriers.

We must not move backward in our progress, even in the face of budget challenges. We must critically examine the impact of any changes to Medicaid, Medicare, or other existing laws based on the effect these changes will have on overall access to quality care. **NBCC remains committed to ensuring all women and men diagnosed with breast cancer have access to the treatment they need.**

Public Policy #1: Guaranteed Access to Quality Care for All

Background

Ensuring access to quality health care is an urgent and longstanding priority for the National Breast Cancer Coalition (NBCC) and an essential component of our mission to end breast cancer. NBCC's grassroots Board of Directors approved a *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All* and works to identify, advocate for, and support implementing laws such as the "Affordable Care Act," marked critical steps toward access to quality health care. Also, NBCC remains committed to protecting vital existing programs such as the Breast and Cervical Cancer Treatment Program (BCCTP).

History of NBCC's Efforts to Expand Access to Quality Care

NBCC has succeeded in making targeted changes to expand access to health care. After years of NBCC grassroots lobbying and influence, Congress enacted the "Breast and Cervical Cancer Treatment Act" (P.L. 106-354) in 2000. The Act authorized enhanced matching funds to states to provide Medicaid coverage to uninsured or underinsured women and men diagnosed with breast or cervical cancer through a federal screening program. Before this Act, women, and men could be denied treatment due to inability to pay, preexisting conditions, or because they exceeded their lifetime health insurance caps. The passage of this law expanded access to health care for thousands of underserved women and men. The Act is an opt-in program for all 50 states, the District of Columbia, five U.S. territories, and 12 American Indian/Alaska Native tribal organizations.

In 2010, NBCC endorsed and advocated for the passage of the "Affordable Care Act" (ACA). This landmark legislation marked critical steps forward in providing access to quality health care for individuals with and at risk of breast cancer. NBCC continues to support the implementation and expansion of the Act. The ACA provides breast cancer survivors and other vital protections from many of the health care system's past practices, including eliminating lifetime insurance caps and restrictions for women and men with preexisting conditions. As a result of NBCC's advocacy, the ACA requires consumer representation on any committees, boards, panels, or commissions formed under the law. Also, insurance companies must cover the routine patient care costs for clinical trial participation and cannot discriminate against an individual based on their involvement in a clinical trial. The law brings the country closer to comprehensive

health care reform that will help the millions of individuals with and at risk of breast cancer.

In addition to safeguarding the Affordable Care Act, NBCC looks forward to working with Congress and the Administration to enact a law(s) that would expand access to Medicare while also offering a private insurance option, automatically enrolling individuals who are not enrolled in other coverage and providing guaranteed benefits including:

- Primary and preventative care
- Hospital services, including emergency services
- Prescription drugs and medical devices
- Maternity, newborn, and reproductive care
- Mental health and substance abuse disorder services
- Habilitative and rehabilitative services
- Dental, vision, and hearing

Any initiative that NBCC supports would also establish a financing mechanism including shared financial responsibility, and where no one can be denied coverage due to an inability to pay.

Public Policy Priority #2: 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.

The cost of breast cancer care continues to rise. Overall, the national cost of cancer care overall 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.[1] This increase does not include 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. Despite the increasing cost of prescription drugs, most approved breast cancer drugs have not been shown to extend life.

Federal agencies spent $243 billion 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. 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.

As patients, we contribute to research by participating in clinical trials, lobbying for research funding, and paying taxes to support it. Our goal is to bring about drugs that will save lives. The research results are often patented, then sold to industry for millions of dollars—the individual doctor and the institution benefit and the companies that manufacture the drugs. But in breast cancer, these drugs rarely extend life and cost so much that they often bankrupt patients and the healthcare system.

Countries like 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. U.S. taxpayers contribute through public university research, grants, subsidies, and other incentives. This means people are often paying twice for their medicines: through their tax dollars and at the pharmacy. It should be

[1] Mariotto et al. Projections of the Cost of Cancer Care in the United States

unacceptable for taxpayers to fund a new medication that the public can't even afford to buy once it hits the market.

Recent reports show that conflicts abound in the research system that currently exists. Moreover, due to the focus on financial gain, patients and the public have lost trust in this system. Passage of legislation to 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 is an essential step towards making healthcare more accessible and saving lives.

Public Policy Priority #3: Ensuring the Participation of Educated Patient Advocates in Science Research and All Levels of Health Care Decision Making

Background

The voice of educated patient advocates must be part of all levels of health care decision-making which affects their lives. Patient participation has been a tenet of the National Breast Cancer Coalition (NBCC) since its inception. NBCC continues to work to ensure that educated patient advocates who represent a constituency have a meaningful "seat at the table" in all levels of health care decision making which affects their lives.

Why Patient Advocates are Necessary

Educated patient advocates provide a unique perspective that others cannot offer. They are the ones who ultimately receive health care services and, along with their families, are required to navigate the complexities of the health insurance and healthcare delivery systems. They have no agenda in the scientific community other than looking for the best science and saving lives they have no conflict of interest. Their perspective cannot be duplicated by the doctors who care for them or the scientists searching for answers, even if these doctors and scientists are patients. A lay advocate perspective is key to moving forward to the end of breast cancer.

Criteria for Patient Advocates

Patient Advocates must:

- Have a patient-led, patient-centered organization with a patient constituency to which they are responsible and accountable;
- Have been personally affected by the disease; and
- Be knowledgeable, trained, prepared, and confident in their ability to participate in the decision-making process of science and medicine.

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