

Testimony of Fran Visco, J.D. President National Breast Cancer Coalition

House Ways and Means Subcommittee on Social Security

March 21, 2019

Thank you, Chairman Larsen, Ranking Member Reed, and Members of the Ways and Means Subcommittee on Social Security, for the opportunity to submit testimony to the record of the hearing this Committee held on March 13, 2019: "Protecting and Improving Social Security".

My name is Fran Visco, and I am a breast cancer survivor, a wife and mother, a lawyer, and President of the National Breast Cancer Coalition (NBCC). My testimony represents the hundreds of member organizations and thousands of individual members of the Coalition. NBCC is a grassroots organization dedicated to ending breast cancer through action and advocacy. The Coalition'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.

We are testifying in support of legislation soon to be re-introduced by Representatives Peter King and Kathy Castor, the Metastatic Breast Cancer Access to Care Act, which would waive all waiting periods for Medicare and Social Security Disability Insurance (SSDI) eligibility for all individuals with metastatic breast cancer.

As you know, individuals with disabilities other than End Stage Renal Disease (ESRD) and Amyotrophic Lateral Sclerosis (ALS) must have received Social Security Disability Insurance (SSDI) benefits for 24 months before gaining eligibility for Medicare. This would 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 as 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.

In 2019, about 268,600 women will be diagnosed with invasive breast cancer, as will 2,670 men, in the United States. About 62,930 new cases of carcinoma in situ (CIS) will be diagnosed. This year, about 41,760 women and 500 men will die of breast cancer. There are approximately 150,000 women in the United States today living with metastatic breast cancer (MBC). There are no statistics that reveal the age of women and men with MBC. While statistics are also not collected for metastatic recurrences which comprise the larger portion of MBC cases, it is estimated that 20-30% of women with breast cancer recur with metastatic disease. 6-10% are diagnosed initially with metastatic breast cancer. The average age of breast cancer diagnosis is 62, the average age of death from breast cancer is 68. The average life expectancy of an individual with metastatic breast cancer is 3 years.

There is a federal precedent for eliminating waiting periods for certain individuals who qualify for SSDI and Medicare benefits based on their disability. In 2001, Congress passed legislation to add ALS as a qualifying condition for automatic Medicare coverage, eliminating the 24 month waiting period. In the last Congress, there was broad bipartisan support for legislation which would build on that precedent by eliminating the five month waiting period for individuals who qualify for SSDI based on their disability.

While we must do more to encourage new treatments and cures, increase access to medical care, reduce health disparities and raise awareness for patients with MBC, eliminating onerous waiting periods for Social Security Disability Insurance and Medicare is a meaningful step for women and their families. Since the average life expectancy for women diagnosed with MBC is only three years, we must eliminate barriers that could delay critical treatment.

NBCC fully supports legislation that would waive the waiting periods for individuals diagnosed with metastatic breast cancer who meet the criteria for SSDI and Medicare. We want to prevent stories like that of Ellen Kay Duffy, a 47-year old nurse from Cedar Falls, Iowa diagnosed with metastatic breast cancer, who died waiting for her Medicare benefits to begin. Individuals like Ellen should not have to wait to have access to the healthcare they have already qualified to receive. There are too many others with similar stories.

Thank you for allowing us to submit testimony for the record. We ask that you support the Metastatic Breast Cancer Access to Care Act when it comes before this Committee. In the meantime, we look forward to continuing to partner with you to ensure all individuals have access to the quality care they deserve.