

## 2023 Lobby Day Tough Questions

### **Level \$150 Million Funding Request for DOD Breast Cancer Research Program**

(1) **Why is NBCC asking for \$150 million this year? Others are asking for more.**

Due to the accountability mechanisms of the DOD BCRP, we know how much money is being spent, how it's being spent, and whether it's being spent effectively. Due to the large number of proposals the Program receives, we also have a good sense of how much money is needed. NBCC believes that \$150 million is the right amount of money for the BCRP for FY24.

This program is very efficient – the administrative costs are extremely low and more than 90% of the funds have gone to grant awards.

(2) **Is the DOD BCRP an “earmark”?**

The DOD BCRP does not fall within the definition of an “earmark” because:

The DOD BCRP funding is not directed to an entity, State, locality or Congressional district. The DOD BCRP allocates funding via a competitive peer-review process.

(3) **Why should money for breast cancer research go to DOD rather than sending it all to NIH?**

The DOD BCRP is a one-of-a-kind program because of its innovative grants and unique structure. It has become a world-renowned model of research due to its efficiency, accountability, and inclusion of consumer advocates at all levels of the decision-making process.

The DOD program does not replicate the research done at NIH and NCI – rather, it complements it, and aims to fill the gaps and fund the kind of research that NIH and NCI don't fund, specifically high-risk, high-return research.

NIH has no program dedicated to breast cancer research.

The DOD BCRP is highly competitive. More than 2000 proposals are received annually and only 10% are funded. The volume of proposals submitted is evidence of the demand for this Program in the scientific community.

The flexibility of the DOD BCRP is unique. Each year the Integration Panel develops the appropriate grant mechanisms to fund the most promising areas of research. These grant mechanisms, address the gamut of needed research, from concept breakthrough level to transformative collaborative and innovator awards , are models that have been developed in the BCRP which have since been adopted by NIH and outside government.

Through its unique two-step peer review process originally recommended by the Institute of Medicine, grant proposals compete based on scientific merit as well as programmatic relevance to ensure that the best science gets funded; it is not duplicative research; and it holds the greatest potential for moving the field of breast cancer research forward.

**(4) Does ARPA-H do away with the need for the DOD BCRP?**

No, while ARPA-H is intended to advance research that will improve cancer outcomes, ARPA-H is focused on platforms that will impact disease broadly, or cancer broadly. It will not focus specifically on breast cancer or any other specific disease. The initial focus of the ARPA-H program will be technology platforms.

**Metastatic Breast Cancer Access to Care Act**

**(1) Would this proposal increase the number of individuals who are eligible for Medicare/Social Security Disability?**

No. It does not at all affect the eligibility criteria for disability under SSDI that confer Medicare eligibility. Those criteria would not change. The bill would only waive the 24 month/5 month waiting periods for individuals already deemed eligible.

**(2) Why should we create an exception (waiver of 24-month waiting period for Medicare and 5-month waiting period for SSDI) only to people 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 some treatments which may extend survival, but no cure. Individuals who qualify are under 65 and diagnosed with metastatic breast cancer already qualify for SSDI and Medicare. However, based on the limited life expectancy of individuals with metastatic disease, an average of 3 years, the waiting periods for receiving these benefits should be waived.

There are federal precedents for this proposal. In 2001, Congress passed legislation to add Amyotrophic Lateral Sclerosis (ALS) as a qualifying condition for automatic Medicare coverage, thus waiving the 24-month waiting period. More recently, legislation has been introduced which would build on that precedent to allow patients with ALS who qualify for SSDI to immediately be eligible for SSDI (thus waiving the five-month waiting period) making them automatically eligible for Medicare as well. NBCC believes that both automatic SSDI and Medicare coverage should also apply to metastatic breast cancer patients who qualify.

### **(3) Weren't these waiting periods put into place for a reason?**

Initially, these waiting periods were put into place to address conditions that could reverse or improve, resulting in the individual no longer deemed to have a disability. In the case of metastatic breast cancer, there is no reversal and no cure.

### **(4) Shouldn't we reform Medicare generally instead of fixing things by a piecemeal approach?**

This bill would not affect Medicare; it addresses waiting periods in the Social Security Act.

### **(5) Why should we single out metastatic breast cancer for a waiting period waiver when there are other serious illnesses for which there is no similar exception?**

The notion that we can't help anyone until we help everyone is not an effective, timely or compassionate approach. For individuals with metastatic breast cancer, time is of the essence. They simply do not have time to wait for benefits that they already qualify for, and that they so desperately need. There is also a great deal of political momentum and grassroots support behind this bill. Thousands of individuals from all across the country are asking their Senators and Representatives to enact this bipartisan legislation as soon as possible. Acting now on metastatic breast cancer does not

preclude in the future determining which diseases warrant this type of legislation and gaining consensus among all of them. There is no reason not to act now on this bill.

**(6) How much is this going to cost?**

The Metastatic Breast Cancer Access to Care Act does not yet have a score from the Congressional Budget office. Based on the data we have regarding the number of individuals who would qualify for this legislation, the cost would be small. We owe it to the individuals dying of metastatic breast cancer to make sure they can immediately access these healthcare benefits that they have already qualified for, and that they deserve immediately.

**(7) Can't the individuals who have metastatic breast cancer find other means of coverage while they wait for their SSDI and Medicare benefits to become available?**

A specific carve-out was already created for individuals with metastatic breast cancer who lose their job and health insurance to be able to qualify for SSDI and Medicare. Metastatic breast cancer is also a condition included under the Compassionate Allowance program expediting approval for SSDI, specifically because of the progressive and fatal nature of the disease. Even with expedited approval, individuals who qualify still have to wait to receive their benefits. There are limited insurance options for individuals with metastatic breast cancer and even if short term options are available in their state, the premiums are often prohibitive for individuals too sick to work and no longer receiving an income. Many short-term insurance plans are wholly inadequate in the face of a serious medical condition. The bottom line is that there is already a program in place for which these individuals qualify; making them wait an arbitrary 5 months and 24 months when many of them will not live to see their benefits is cruel and unnecessary.

**(8) Social Security is running out of money so how can waive these waiting periods now?**

Issues with the Social Security Trust Fund are longstanding and have not stopped Congress from waiving the onerous and arbitrary waiting periods in other instances (ALS.) For many years Congress has considered solutions to the Trust Fund's problems and denying benefits to eligible individuals has never been a suggested solution.