

19 October 2018

Professor Robyn Ward  
Chair, Medical Services Advisory Committee  
Department of Health and Ageing  
MDP 851  
GPO Box 9848  
CANBERRA ACT 2601

Dear Professor Ward

**RE: Germline BRCA mutation testing to determine eligibility for Talazoparib**

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We support, inform, represent and connect people whose lives have been affected by breast cancer. BCNA represents more than 120,000 individual members and 300 Member Groups from across Australia.

BCNA is pleased to support an application to MSAC from Pfizer for germline BRCA mutation testing as a co-dependent service to determine eligibility for talazoparib treatment in women with locally advanced or metastatic HER2-negative breast cancer. We understand that only patients who are germline BRCA mutation positive will be eligible for treatment with talazoparib.

Talazoparib has been shown to significantly extend the median progression free survival for women with a germline BRCA mutation diagnosed with locally advanced or metastatic breast cancer. Results from the phase III clinical trial EMBRACA found that women who received talazoparib had a median progression free survival of 8.6 months compared to 5.6 months for women who received standard therapy. The trial also found that 37% of the women who received talazoparib did not have disease progression or death at one year compared to only 20% of women treated with standard therapy.

BCNA hopes that these findings will lead to a much needed new treatment option for Australian women with locally advanced or metastatic breast cancer who have either the triple negative or hormone positive forms of the disease. We hope that these groups of patients will be able to access the drug in Australia outside of clinical trials in the future.

PARP inhibitor drugs like talazoparib are an important advancement, particularly for those women with triple negative breast cancer whose only other option is chemotherapy, with all of the associated toxicities that this entails. To have the opportunity to take an oral targeted medication that is well tolerated is a game changer for this group of patients who have been denied new treatment options for so long.

*I consider myself so fortunate to be receiving Talazoparib via the EMBRACA clinical trial, it has kept my breast cancer and bone metastases stable for almost two years. Being eligible for this targeted therapy has been the only time that I have felt grateful to carry a BRCA2 mutation.*

*From a physical perspective, Talazoparib is allowing me to live a life where I don't feel completely inhibited by my disease - I'm not bedridden, I can exercise, I don't have debilitating side effects requiring constant care and people would not know that I have cancer by looking at me.*

*I am positive I can take the liberty of speaking on behalf of all people with metastatic breast cancer when I say, we know that our disease cannot be cured but we want priority access to affordable medications that can give us the best quality of life with minimal side effects. Time is not on our side and any opportunity to receive a promising treatment option is always welcomed.*

- Rachele, age 38, participant in the EMBRACA trial

BCNA believes that women who may have a germline BRCA mutation and who may benefit from treatment with Talazoparib should be able to access testing at an affordable price. We know from our 2017 *Financial Impact of Breast Cancer Project* that the high out-of-pocket costs of diagnostic tests and scans often exclude women from accessing procedures that are not available through the MBS even if the tests or scans are recommended to them by their doctors. The AIHW's August 2018 report, *Patients' out-of-pocket spending on Medicare services, 2016-17*, confirms BCNA's findings regarding the variation that exists in out-of-pocket costs for patients with breast cancer. It is of great concern to BCNA that the 2016-17 ABS Patient Experience Survey contained in the AIHW's report found that 7.6 per cent of people aged 15 years and over either delayed or did not seek a specialist, GP, imaging or pathology service that they had needed because of cost.<sup>1</sup> This represents approximately 1.3 million Australians,<sup>2</sup> and shows that high out-of-pocket costs can be prohibitive for individuals, even when their treating teams recommend a test, scan or other service. .

Affordable and equitable access to new and innovative cancer treatments is of vital importance to our members and will remain an advocacy priority for BCNA. The inclusion of BRCA mutation testing on the MBS for the purpose of determining whether a new targeted therapy may be of benefit to women would help to make this test an affordable option for all women living with locally advanced or metastatic breast cancer.

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<sup>1</sup> Australian Institute of Health and Welfare 2018. *Patients' out-of-pocket spending on Medicare services, 2016-17*. Cat. no. HPF 35. Canberra: AIHW.

<sup>2</sup> Ibid.

We believe that amendment of MBS Item Number 73295 to include talazoparib use in breast cancer is an important step to help bring this important new therapy to Australian women who may benefit from it. Importantly it will help women avoid having to grapple with the uncertainty and distress of having to self-fund the cost of \$1200 for genetic testing to determine whether they may benefit from the drug.

BCNA would be very happy to meet with you to further represent the consumer voice on this important issue should that be helpful to you.

Yours sincerely



Danielle Spence  
Director Advocacy, Policy and Programs