

# SO BRAVE

Australia's Young Women's Breast Cancer Charity

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The Hon. Michael Sukkar MP  
Minister for Housing and Assistant Treasurer  
Parliament House  
CANBERRA ACT 2600

[cc the Hon Greg Hunt MP, Minister for Health and Aged Care  
Senator the Hon Marise Payne, Minister for Women]

24 January 2022

Dear Minister

## So Brave – Australia's Young Women's Breast Cancer Charity - 2022-23 Federal Pre-Budget Submission

I am pleased to provide the So Brave – Australia's Young Women's Breast Cancer Charity – 2022-23 Pre-Budget submission.

On behalf of young women across Australia, as So Brave's Founder and Managing Director and as a two-time breast cancer survivor, I implore the Coalition Government to consider these critical Women's Policy issues and funding in relation to young women in this next budget.

### Young women and breast cancer in Australia

Australia has one of the highest rates of breast cancer in the world and our incidence has increased in recent years from 1 in 8 women diagnosed in her lifetime by age 85 to 1 in 7<sup>1</sup>. This incidence (indeed since my own initial diagnosis in 2014) has grown from ~800 women aged 20-39 being diagnosed every year **to over 1000**: an additional **~8000** young families affected economically, socially and mentally in less than a decade.

So Brave is a growing community of young women and their friends, families and colleagues passionate about changing the conversation for young women and breast cancer. We want to recognise and to challenge the unmet needs of young women in this space:

- the young women who are shocked with a diagnosis of this devastating disease,
- the women who need better education and understanding of their own risk,
- the importance of self-health advocacy and
- most important of all, changing the **disproportionately higher death rate** of young women diagnosed with breast cancer.

The *National Women's Health Strategy 2020-2030* identifies breast cancer<sup>2</sup> as the leading cause of death in women aged 25-44 years old.

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<sup>1</sup> NBCF 2022 <https://nbcf.org.au/about-breast-cancer/breast-cancer-stats/>

<sup>2</sup> *National Women's Health Strategy 2020-2030, Figure 4: National burden of disease across the life course: 25 to 44 years: Anxiety and depressive disorders are leading nonfatal disease burden. Burden due to intimate partner violence was highest among women aged 40 to 44 years. Suicide/self-inflicted injuries and breast cancer are the leading causes of fatal burden.*

For the past two Pre-Budget Submission rounds and in our letters to all Ministers, Members and Senators, So Brave has expanded on some of the ways that the Government could fund better health education, research and support of young women, particularly through the Morrison Government's commitment to Women's Policy.

Unfortunately, at present, the Women's Policy response has failed to recognise the specific needs of young Australian women, particularly where it pertains to the disproportionate impact that breast cancer has at this foundational stage of life.

Specifically, women aged under 40 are ineligible to access any breast cancer-related or mammography screening programs in Australia<sup>3</sup>. Therefore, the extraordinary funding of BreastScreen has **no impact** on reducing young women's breast cancer rates. So Brave is of the view that this has the effect of doing the opposite and instilling false sense of risk.

### Breast cancer screening in Australia

According to the recent *BreastScreen Australia monitoring report 2021*<sup>4</sup> only 55% of women aged 50-74 accessed BreastScreen services. The initiative within the *Women's Budget Statement*<sup>5</sup> last year to extend funding to support women to access BreastScreen and further promotion that breast cancer screening does indeed commence from age 40 was a very welcome step in supporting more Australian women. There remains however, a core demographic of women aged under 40 who are not eligible for BreastScreen; and face significant costs when they need scans to confirm a breast cancer symptom.

Most of the misinformation we encounter about breast cancer risk in young women results from a misunderstanding created because of the age of eligibility and invitation for mammograms. Even women in their 40s, who are eligible for BreastScreen are largely unaware of the service because promotion focusses so heavily on women aged 50-74.

Through our #breastaware for life education program, we've worked with more than 1000 young women at senior high schools and university and in over 60 communities across metropolitan and regional Australia to discuss the statistics of breast cancer in young women, the lifetime risks of breast cancer, the importance of self-examinations and the necessity for confident self-health advocacy. Overwhelmingly, young women are largely unaware of their risk of breast cancer, and the critical nature of self-breast checks as their only (current) diagnosis pathway.

According to the Royal Australian College of GPs report last year<sup>6</sup>, gender bias in medicine is still putting women's lives at risk and delayed diagnosis in women even more apparent in younger women. Over the past six years, So Brave has continued to meet young women diagnosed with the disease, young women eager to share their experiences as young breast cancer patients.

This issue of gender bias in medicine by health care professionals treating young women with breast symptoms is all too common. We've found that many young women seek medical support from their GPs, only to be given feedback they are 'too young', or that they don't have any of the risk factors to support getting their symptom/s investigated. Despite the updated and revised

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<sup>3</sup> Notwithstanding a significant family history, knowledge of same and GP support to access specific screening for high-risk young women.

<sup>4</sup> AIHW 2022 <https://www.aihw.gov.au/reports/cancer-screening/breastscreen-australia-monitoring-report-2021/summary>

<sup>5</sup> Budget 2021-22 [https://budget.gov.au/2021-22/content/womens-statement/download/womens\\_budget\\_statement\\_2021-22.pdf](https://budget.gov.au/2021-22/content/womens-statement/download/womens_budget_statement_2021-22.pdf)

<sup>6</sup> RACGP 2021 <https://www1.racgp.org.au/newsgp/clinical/gender-bias-in-medicine-and-medical-research-is-st>

Cancer Australia *Guide for General Practitioners: the investigation of a new breast symptom*<sup>7</sup> in 2017, GPs and other primary healthcare providers continue to deny young women. Indeed some radiologists have been reported to refuse to undertake a mammogram, even when it has been requested on a GP's referral. Breast Cancer Network Australia's *State of the Nation* reported overwhelming reports of young women being dismissed by GPs as 'too young to have breast cancer' if aged under 40<sup>8</sup>.

The Commonwealth Government has an important role to play in this significant area of Women's Policy. Empowering young Australian women with the knowledge and confidence to self-advocate for their health, particularly their own breast health, is one area that So Brave believes the Government can fund and in doing so, measurably improve the promotion of public health to the benefit of all Australian women. In addition, the Government could reissue the 2017 Cancer Australia advice to GPs to support doctors and radiologists to understand this issue is an area of Women's Policy that the Government views as important, with significant benefits to Australian women. In our previous Pre-Budget submission to you, we estimated this public health campaign would cost the Budget \$4 Million.

#### A note about scans and young women

While it is well established that screening mammograms are not suitable for young women, once an anomaly is found and a GP is willing to undertake and refer for further testing, the next impediment for young women is access to diagnostic scans (diagnostic mammogram, ultrasound and/or MRI). Our members report significant expenses for diagnostic and surveillance ultrasounds, mammograms and MRIs, and many are ineligible for bulk-billed or Government subsidised screening. One young breast cancer survivor brought to our attention, the issue of out-of-pocket expenses for breast MRIs. In her situation, her mammogram was clear, and her ultrasound showed only a tiny shadow, but had she not proceeded (at her surgeon's insistence) to get the MRI, she would not have known that 3 tumours were already growing in her breast. She was financially capable of affording this expensive diagnostic scan, but many young Australian women would not, to their detriment and that of the Budget.

After investigation of her report and that of many young women, I discovered quite by chance that not all MRIs are created equal. While it is well known that private radiology companies can set their own uncapped prices for scans, it is not widely understood that the Commonwealth Government funds some of these MRI machines<sup>9</sup> (and therefore enabling these private companies to offer bulk-billed services). This information is made public, if you know that you need to access it. However, the difference between a Government-funded (Medicare eligible) machine and one that is not isn't widely understood within the community; meaning that many young women are forced to pay in the vicinity of \$450 - \$700 for a single MRI scan (often done annually as part of breast cancer monitoring).

**There is an opportunity for the Coalition Government to share this distinction about the availability and funding of Medicare eligible MRI machines through a public awareness campaign to extend**

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<sup>7</sup> Cancer Australia 2017 [https://canceraustralia.gov.au/sites/default/files/publications/investigation-new-breast-symptom-guide-general-practitioners/pdf/2017\\_inbs\\_gp\\_card.pdf](https://canceraustralia.gov.au/sites/default/files/publications/investigation-new-breast-symptom-guide-general-practitioners/pdf/2017_inbs_gp_card.pdf)

<sup>8</sup> Breast Cancer Network of Australia 2018 <https://www.bcna.org.au/media/6656/sotn-report-lowres.pdf>

<sup>9</sup> Australian Department of Health 2020 <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mri-index>

awareness of public health outcomes and improve access and equity of these machines, particularly for young women. Unfortunately this scan is so cost-prohibitive that many young women will make the choice not to have this potentially critical health information.

There is also a fiscal opportunity for the Government to extend subsidised MRI screening for young women and to increase the number of Medicare eligible MRI machines to improve health outcomes as part of ongoing improvements in Women's Policy.

The Government is uniquely placed through Medicare to affect and deliver widespread and immediate change for every single young Australian woman who needs a diagnostic ultrasound, MRI or mammogram to confirm their breast symptom is or is not breast cancer. For young women in particular, that initial diagnostic ultrasound, MRI or mammogram that could lead to an early diagnosis is still incredibly cost prohibitive to the individual. **There is still an important fiscal opportunity for the Government to extend subsidised diagnostic and surveillance mammograms and ultrasounds to young women as part of ongoing improvements in Women's Policy, particularly as a response to acknowledge the lack of access to the free National BreastScreen screening program.**

#### Women's Policy opportunities

So Brave acknowledges that the COVID-19 pandemic has placed unprecedented pressure on Budget outlays and as such, we have also included non-fiscal opportunities for the Government to consider to support our mission through the 2022-23 Budget if funding was only the final hurdle. So Brave submits to the Coalition a suite of complementary policies that should be in consideration for appropriation, including:

- A National Education Program for young Australian women – university and school programs to educate young people about the importance of being body and breast aware to reduce the inherent Medical gender bias.  
So Brave recommends that the Government provides So Brave with funding to deliver an initial rollout of the #breastaware in schools program with an investment of \$1 Million.
- A National Education Program for primary healthcare providers – GPs and radiologists – to raise awareness of their role in educating young women about breast awareness and investigating further through ultrasound, MRI and mammogram where a symptom has been identified. As part of this education program for primary healthcare providers - promotion of and access to Medicare support for high-risk young women:
  - o MRI screening program<sup>10</sup>
  - o BRCA testing<sup>11</sup>

So Brave recommends that the Government direct Cancer Australia should initiate a review, revise and redistribute an update to the 2017 *National Guidelines for investigating a breast symptom* in conjunction with a national health promotion campaign in collaboration with the previous co-signatories, most importantly RACGP. This program could be delivered within a \$250000 budget.

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<sup>10</sup> Cancer Australia 2022 <https://canceraustralia.gov.au/clinical-best-practice/breast-cancer/screening-and-early-detection/mri-high-risk-women>

<sup>11</sup> BCNA 2017 <http://beacon.bcna.org.au/2017/11/medicare-rebates-for-genetic-testing/>

- Extension of eligibility criteria to allow all breast cancer patients and survivors to access the Health Care Card and its benefits – reducing the impact of ongoing medical and pharmaceutical expenses associated with this chronic illness. Reducing each individual breast cancer survivors recommended 10 year estrogen treatment on drugs like Tamoxifen, Aromatase Inhibitors and Zoladex from \$10,200 to \$163.20.<sup>12</sup>  
So Brave recommends that the Government provides access to reduced medical and pharmaceutical expenses by allocating Health Care Cards to all breast cancer patients.
- Fund research that specifically focusses on the prevention and diagnosis of breast cancer – particularly in young women aged under 40 who aren't part of the existing *BreastScreen* mammography screening age bracket. Our first collaborative research project in 2022 would create world-first data and understanding of BRCAness in young women for as small an investment as \$125000 – testing 1000 young Australia breast cancer patients BRCAness through germline and somatic DNA testing. Our second collaborative research project, the breast cancer blood test will revolutionise breast screening measures in Australia and for an investment of \$5 Million would provide sufficient data to prove its efficacy for future use. So Brave recommends the Government support breast cancer research that specifically impacts young breast cancer patients.
- Improve the language around, access to and funding of Additional Child Care Subsidy (Child Wellbeing Subsidy) for childcare services for women undergoing breast cancer treatment beyond 13 weeks. Breast cancer treatment can often continue intensively for up to 18 months, and for some women, years following their initial diagnosis.  
So Brave recommends that the Government consider expanding the definition of access – women who need this support do not need to be told their children need to be classified as 'at risk of serious abuse or neglect' in order qualify. The Government should consider apportioning some of the already budgeted \$1.7 Billion allocated in 2021 towards this initiative.
- Improve access to bulk-billed preventative IVF services for young women prior to chemotherapy, particularly women in regional and remote Australia. Deloitte's *Financial Impact of Breast Cancer*<sup>13</sup> conservatively estimated in 2016 an individual's IVF preservation consult, egg collection, freezing and storage at \$4375 minimum. Not all providers offer bulk-billing in these circumstances and price fluctuates substantially.  
So Brave recommends that the Government mandates all providers to offer bulk-billing IVF preservation services to young women undergoing breast cancer, thereby removing these costs to the individual.

<sup>12</sup> Based on 2022 PBS rates for general patients (\$42.50) and concession holders (\$6.80) x Tamoxifen or AI + Zoladex/ month over 10 years

<sup>13</sup> Deloitte Access Economics 2016 <https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-financial-impact-breast-cancer-180917.pdf>

## The future

We are working with the Queensland Government on information provision to young breast cancer patients. In December 2021, the Queensland Minister for Women, the Hon Shannon Fentiman awarded So Brave with \$14700 in funding to distribute information to young women – changing the way young breast cancer patients experience their diagnosis and changing the way young women view breast cancer.

In 2021, we initiated introductions and presentations about pioneering breast resensation reconstruction surgeries to Australian breast and plastic surgeons with leading US surgeons resulting in these practices now being trialled by surgeons in Sydney to the great benefit of Australian women as Australia is now the only country outside of the US to offer these surgeries. We will continue to advocate and support surgeons to bring these techniques to Australia in collaboration with the Royal Australian College of Surgeons, BreastSurgANZ, the Plastic Surgeons Association of Australia and leading Australian surgeons.

We are working with several Australian researchers on significant opportunities to change the way breast cancer is diagnosed and treated. One such very exciting initial development is the potential for a blood test to screen and monitor breast cancer. In a situation reminiscent of the change in prostate cancer screening from a physical exam to blood test, So Brave hopes that once this blood test is satisfactorily proven, it could be the way forward for all women. This blood test has the potential to be a highly effective resulting in real Budget savings into the future and improving breast cancer early diagnosis and early recurrence detection rates across age demographics.

Similarly, So Brave looks forward to working with researchers on genetic marker testing to ensure that cancer is treated with the best medicine available for each person's specific disease. This has the potential to reduce public health costs within the Commonwealth Health Budget, and significantly improve survival rates from not just breast but other cancers and diseases.

So Brave is a unique, young and vibrant organisation, changing the conversation around breast cancer in young women across the country. We have identified an urgent need to address the gaps for young women and we look forward to working with you to continuing to do this in 2022.

We very much look forward to your support of our Pre-Budget Submission and your support of women's health and in particular Women's Policy for young women.

Sincerely,



Rachelle Panitz  
Managing Director and Founder  
So Brave