

# Neo-adjuvant Herceptin for early or locally advanced breast cancer

## PBAC Submission July 2012



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### Introduction

Breast Cancer Network Australia (BCNA) welcomes the opportunity to provide comment on the major submission about Herceptin (trastuzumab) to the Pharmaceutical Benefits Advisory Committee (PBAC) to “extend the current Section 100 Efficient Funding of Chemotherapy (Public Hospital or Private Hospital/Clinic) listing to include:

- initial and continuing treatment of human epidermal growth factor receptor-2 (HER2) positive early breast cancer commencing concurrently with neoadjuvant chemotherapy; and
- initial and continuing treatment of HER2 positive locally advanced breast cancer commencing concurrently with neoadjuvant chemotherapy.”

BCNA supports the major submission to extend the current listing for Herceptin to allow for its concurrent use with neoadjuvant chemotherapy in women with early or locally advanced breast cancer. We believe this extension should be implemented immediately.

### About BCNA

BCNA is the peak national organisation for Australians personally affected by breast cancer. We empower, inform, represent and link together people whose lives have been affected by breast cancer.

BCNA represents more than 70,000 individual members and 300 Member Groups from across Australia.

BCNA works to ensure that women diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible – no matter who they are or where they live. BCNA is represented by the Pink Lady silhouette, which depicts the organisation’s focus, the women diagnosed with breast cancer.

### About our Submission

BCNA emailed an existing email list of 252 women who have taken Herceptin for the treatment of breast cancer. We asked women to respond to the questions below which are based on the template questions for consumer submissions included on the Department of Health and Ageing website. We received responses from 66 women, and have summarised them below.

Throughout the submission we have highlighted the responses from women taking Herceptin in the neo-adjuvant setting. We have also included a summary of responses from women treated in the adjuvant setting, as we believe that their personal experiences of the advantages, disadvantages, impact on themselves, their families and friends and other benefits associated with Herceptin will also be relevant and applicable to women treated in the neo-adjuvant setting.

## Questions

1. Are you currently, or have you previously, taken Herceptin for your breast cancer? If yes, please state whether your breast cancer is/was early or locally advanced (if you know), whether you took Herceptin before or after your surgery, and how well you think the treatment worked for you.

Of the women who responded to our email:

- 2 women took Herceptin in the neoadjuvant setting for early breast cancer
- 4 women took Herceptin for locally advanced breast cancer in the adjuvant setting
- 54 women took Herceptin to treat early breast cancer in the adjuvant setting
- 5 women took Herceptin for a range of other reasons including a diagnosis of inflammatory breast cancer, and two women for a local recurrence in the skin.

2. What are/were the benefits of Herceptin for you? Are/were there any disadvantages of Herceptin?

### Neo-adjuvant Herceptin

The two women who took neo-adjuvant Herceptin specifically highlighted the benefits of the tumour shrinking prior to surgery. They highlighted that this meant that the surgeon was able to obtain clear margins, as well as reducing the amount of tissue removed.

*"I think the treatment went extremely well for me as I started off with a sizeable tumour and went in to surgery with the tumour shrunk to the size of my pinkie thumbnail."*

*"The benefits of Herceptin as I understood it was to shrink the growth of the tumour as much as possible prior to surgery because there wasn't enough clear margin around the local site, and to kill any residual cancer cells (if any) post surgery to ensure I had the best possible long term outcome for my future. I do not feel there were any disadvantages to taking Herceptin. I don't believe I had any side effects. It was definitely less taxing on the body compared with Chemotherapy. I felt very comfortable knowing that this drug was a targeted drug for my particular type of cancer and this it gives me an increased chance of long term survival."*

They also highlighted the psychological benefits they felt at being able to "see" the tumour shrink.

*"...it was very empowering to actually feel or see the tumour shrinking when shown scans. I could actually feel it shrinking which was so exciting. I felt like I was winning the battle, that something positive was coming out of all the treatment I was receiving, even when I felt so sick from the chemo."*

### Adjuvant Herceptin

Women with early or locally advanced breast cancer identified a range of benefits of taking Herceptin, the main ones being that they are still alive as a result, or that they felt empowered as they saw that taking the drug was a way of doing something to

reduce the risk of their breast cancer returning. For some women this was a more salient point than others.

*“There were no disadvantages for me – I felt like I was given more insurance to kill off any lingering cancer cells.”*

*“Knowing I had a life line to treat the HER2 was/is a huge advantage - particularly mentally.”*

*“I am still here three years on and can be around to see my children grow up.”*

*“The peace of mind I had from the hope that it was directly attacking the cancer cells and the fact that I was able to access it before I developed secondaries. My sister was also HER2+ (she was diagnosed in 1995), and was not able to access Herceptin until after she developed secondaries in 2000. She died in 2004.”*

*“Without Herceptin, I would have had a life filled with the fear that breast cancer was going to kill me. Now that I've had Herceptin treatment I feel that I'll be around for my husband and our kids for many years to come. I felt that I was doing something proactive to keep the cancer away!”*

A number of women who had received Herceptin to treat their early breast cancer in the adjuvant setting highlighted how grateful they were that Herceptin had been available to them through the PBS.

*“We would have found it extremely stressful if this drug had not been available to me on the PBS. I was aware that my medical oncologist was keen to commence Herceptin as soon as she could. I believe that it has been a very significant factor in saving my life. I live in hope that this will continue to be the case for years to come.”*

*“The benefits were it was available free, and I did not experience the side effects associated with my previous chemotherapy.”*

*“If it wasn't on PBS the cost would be far too high to be able to have the treatment.”*

*“Had it not been on the PBS, this wonder treatment would have been financially beyond our means (although my husband would have mortgaged our home if needs be.)”*

*“I live in a regional city in NSW and travelled 200kms to have my breast cancer diagnosed and treated. The additional expense of travel and accommodation weighed heavily on me and my family. It was such a relief to know that Herceptin, a life-saving drug, was available for me on the PBS. It made coping with a life threatening illness that much easier.”*

*“If Herceptin wasn't covered, we wouldn't have been able to afford to pay for it - unless we sold our house. Cancer is already a big enough financial burden, adding to it by charging for Herceptin isn't going to help patients or their families.”*

Rural women receiving Herceptin in the adjuvant setting talked about the benefits of being able to have their Herceptin treatment at their local hospital, rather than travelling long distances.

*“I was able to have the treatment at my local hospital in Traralgon (all other treatment including chemo and surgery was carried out at in Melbourne), and finally, that I did not have to pay for it.”*

*“Other benefits came from being able to have the treatment here at my local (regional) hospital and not have to travel to Brisbane.”*

Many women taking Herceptin in the adjuvant setting also talked about the limited to zero side effects they experienced as a key benefit of the drug, particularly when compared with the side effects that many experienced as a result of chemotherapy. The side effects from Herceptin that women considered minor ranged from experiencing a warm or flushed face, through to a slight headache, fatigue, or a slightly runny nose or flu-like symptoms. Some women also commented on the discomfort they experienced at having to undertake heart monitoring.

*“I did not suffer any side effects from the Herceptin so I was able to do all the things that I normally do. That did surprise me.”*

*“Obviously, it significantly improves my chances of long term survival. Side effects were minimal - at times I experienced flu like symptoms and/or tiredness. My MUGA scans and echocardiograms indicated no change in my heart function.”*

*“The side effects were minor compared with other chemotherapy and the radiotherapy I had received earlier, and the most confronting part of Herceptin treatment was the necessity to have regular gated heart pool scans (which I hated).”*

*“The only disadvantage from my point of view was the regular gated heart scans which I did not “enjoy”, but they just had to be done.”*

**3. How is/was your life, and that of your family, improved by Herceptin? Please explain why.**

Neo-adjuvant Herceptin

Women receiving Herceptin in the neo-adjuvant setting highlighted that they, and their families, felt more positive about their treatment, and their survival prospects as a result of taking Herceptin.

*“Knowing that it was a drug that can treat my type of cancer and that this was a targeted drug, gave me and my family hope, and strength.”*

*“...having the tumour shrink before surgery meant that I went in to surgery knowing that they could remove the tumour with a greater clear margin than when I initially presented for treatment. And now that I'm 3 years in remission, I believe the drugs prescribed will give me many more years (decades!) with my family.”*

Adjuvant Herceptin

Many women highlighted that their lives and those of their family was improved through the confidence they felt as a result of taking Herceptin.

*“Peace of mind, knowing that Herceptin was giving me an extra fighting opportunity to continue living.”*

*“It gave us a more positive outlook on the long term outcome.”*

*“More peace of mind knowing that the extra treatment will hopefully prevent recurrence. It is now 7 years since my treatment in 2005.”*

*“I think for me and my family it gave us great confidence that we were doing all that we could and that this drug was a great breakthrough. In some ways I felt grateful for having a type of cancer that could be treated with Herceptin.”*

*“I regard Herceptin as an absolute life-saver. It gave me and my family confidence that I had a treatment that would kill the ‘beastie within’ and give me a good life.”*

*“I think that knowing Herceptin was available and affordable gave me and my family great peace of mind and absolute confidence that I would survive what was a pretty dire original diagnosis.”*

*“My family’s life has been improved by me being around longer!”*

*“The treatment was a snap. It enabled us to move on very quickly and gave us great hope. I continue to be very grateful. Herceptin enabled me and my family to move on with total confidence.”*

*“With a young family my long term survival means an opportunity for a ‘normal’ life for my family. My worst fear when embarking on ‘the journey’ was the thought of my children growing up without their mother and my husband having to be mum and dad.”*

*“The benefits for me and my family are that I am still alive to write this answer for you.”*

Other improvements highlighted by women taking Herceptin in the adjuvant setting included the ability to maintain their usual lifestyle, or to undertake new adventures while still undergoing treatment.

*“Able to resume active and healthy life style after chemo while getting regular Herceptin treatment.”*

*“I scheduled treatments so that I could ski 3 days each of the weeks between treatments and also a 15 day trip to the Kimberly between 2 treatments.”*

*“My life has been immeasurably improved as I doubt if I would be here without having had the treatment. I have travelled the world and Australia extensively living my motto of ‘Get as much as you can out of every day’. I have now seen my daughter married and have experienced much joy in being at the birth of my grand-daughter three years ago and continue to love this little poppet every day of my life.”*

**4. What other benefits can you see from having Herceptin that is given to women before surgery, on the PBS (for example fewer hospital visits, reduced time off work etc)?**

Neo-adjuvant Heceptin

The two women taking neo-adjuvant Herceptin also highlighted the financial burden of having to pay for treatment, and the impact this has.

*“It would be great to reduce the financial burden of receiving Herceptin prior to surgery...It’s just not fair. Treatment decisions should never have to come down to affordability for the individual. Also, Herceptin doesn’t have the same debilitating side effects as chemotherapy, Herceptin is a fantastic targeted drug that women can take and continue on with their lives, such as work, manage family life, etc.”*

### Adjuvant Herceptin

Some women taking Herceptin in the adjuvant setting highlighted that the limited side effects meant that they could continue with their usual lives, reducing the impact on health services. However this was not a relevant consideration for all women.

*“Herceptin has given my family and me choices which I think every person suffering from HER2 positive cancer deserves. I guess obviously it starts the process of getting well earlier which does mean less time off work, fewer hospital visits and therefore less burden not only on the sufferer and family but also on health services. I am lucky that Herceptin was developed and it seems criminal to me that it cannot be used to help people at a time when every bit helps.”*

*“Fewer hospital visits and reduced time off work seem to me to be irrelevant when facing an illness such as breast cancer. Surely the most important thing is to have the best treatment available, no matter what. I have to say that I am just 71 years old!! Younger women would have very different views, I’m sure!”*